The Dissertation Committee for Yolanda Rodríguez-Escobar Certifies that this is the approved version of the following dissertation:

COPING STRATEGIES AMONG MEXICAN AMERICAN WOMEN LIVING WITH HIV

Committee:

Elizabeth C. Pomeroy, Supervisor

Diana M. Dinitto

Lori K. Holleran Steiker

Michele A. Rountree

Martha Menchaca

COPING STRATEGIES AMONG MEXICAN AMERICAN WOMEN LIVING WITH HIV

by

Yolanda Rodríguez-Escobar, B.A., M.S.W.

Dissertation

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Doctor of Philosophy

The University of Texas at Austin

December 2010

Dedication

This dissertation is dedicated to my *querida familia*. To my parents, Arturo and Olga Rodríguez, who taught me the values of respect and integrity which have helped to shape the person that I am today. To my husband, Manuel, who has stood by me throughout the years, as together, we have reached our educational goals, and made an effort to pass this legacy on to our children. To my children, Desirée, Felicia, Manuel Arturo, and Analysse, who continue to amaze me in their own educational accomplishments and career paths. To my grandchildren, Julia, Jeremy, Jocelyn, and Jianna, may they take note that they too can reach for the stars and remember their Grandma Tiny's words of advice: *Si Se Puede!* And lastly, I would like to dedicate this study to three very special women, Christina, Bertha & Lucia for sharing their lives with me and who taught me the true meaning of grace and dignity.

Acknowledgements

There is a long list of individuals that I must recognize, beginning with Laura Lein. I will always be indebted to you for serving as my initial Chair and for supporting me from the beginning of my research through my proposal defense. To Beth Pomeroy, who believed enough in me and agreed to serve as my second Chair and helped guide me to the finish line. I wish to acknowledge the rest of my dissertation committee for assisting in the development of my research and editing of my final work, Drs. Holleran, DiNitto, Rountree, and Menchaca. Thank you, Dean White, for displaying your unending support throughout my tenure at UT. Words cannot express how much I have appreciated your genuine concern for my successful completion of my studies.

To my friends, David and Heng-Rue, who were in my cohort and shared in this journey. To Nancy, Olivia, and John, who went before me and showed me the way. I would like to acknowledge my wonderful friend, Richard Longoria for spending endless hours discussing our research topics and for providing me the support I needed. Thank you for giving me the confidence necessary to keep my eye on the prize.

Most importantly, I need to acknowledge the support I received from the love of my life, my husband, Manuel, my children, and the rest of my extended family whose undying support guided me through the completion of my doctoral studies as a first generation student.

And lastly, this research would not have been possible without the beautiful and courageous *Mujeres* who participated in this study. These are the women who have inspired me and taught me to recognize the strength in taking life "un dia a la vez." *Mil Gracias!*

COPING STRATEGIES AMONG MEXICAN AMERICAN WOMEN LIVING WITH HIV

Publication No._____

Yolanda Rodriguez-Escobar, PhD

The University of Texas at Austin, 2010

Supervisor: Elizabeth C. Pomerory

Abstract: The literature has documented the disproportionate rate of HIV infection among women of color, mainly, African American women and Latinas. The current trend shows that the number of cases affecting these sub-populations will continue to increase. A gap exists in the literature in understanding the coping strategies of Mexican American women living with HIV. Using an ethnographic approach, this research answers the central question of how Mexican American women live with and make meaning of their HIV status. This researcher used a sample of 15 Mexican American women living with HIV who had participated in the *Mujeres Unidas* support group in San Antonio, Texas. The most common theme found was how the role of faith was central to their lives. It was clear that this belief served as their primary source of strength. The findings suggest the need for social workers to examine new paradigms, strategies, and interventions that focus on the broad social, economic, and community factors that put

Mexican American women disproportionately at risk for HIV. These factors include poverty, income and wealth inequality, poor quality of life, racism, sexism, and low socioeconomic status, which are all major risk factors for ill health and health disparities. This research demands that social workers and other researchers examining coping skills address the issues of resiliency and strengths perspective in understanding the ways in which the life journey unfolds for Mexican American women living with HIV. Although, this study focused on Mexican American women, future research is needed to compare this group to other women living with HIV as there may be cultural differences that exist. Additional research is needed in studying the role that religion plays in the lives of Mexican American women living with HIV as many of the participants revealed that they left things up to "God's will." Among the unexpected findings, the theme of viewing their situation from the perspective of "Un dia a la vez" (One day at a time) suggests that the belief that the course of their lives is not necessarily under their control which could be related to *fatalism* (fatalism).

Table of Contents

List of Tables

Coping Strategies Among Mexican American Women Living with HIV

Chapter One

Introduction to the Study

This study explored the experiences of Mexican American women living with HIV. Specifically, this study focuses on the coping strategies these women use to make meaning of their experience living with their diagnosis.

Purpose of Study

The study explores to the role of culture plays in decisions about seeking treatment and how culture influences coping strategies for Mexican American women living with HIV. This study uses the qualitative research methodology of ethnography to examine the coping strategies and how these women make meaning of their HIV status.

The ethnographic approach to studying the population identified is an appropriate research methodology. In contrast to more structured interview approaches, ethnography allows thematic content to emerge from interviews without strongly pre-imposing researcher's definitions about what is important (Spradley, 1979). It allows the researcher to describe participants' meaning of what living their daily lives with HIV is like. This method facilitates the documentation of the lived experiences and coping strategies as ethnographic interviewing accesses cultural knowledge by focusing on the details and context of experience (Creswell, 1998; Spradley, 1979). Ethnography usually refers to forms of social research that involves explicit interpretation of the meanings and

functions of human actions, the product of which mainly takes the form of verbal descriptions and explanations, with quantification and statistical analysis playing a subordinate role at most. Furthermore, ethnography has been claimed to represent a uniquely humanistic and interpretive approach (Atkinson & Hammersley, 1998). Therefore, an ethnographic approach assisted in examining cultural factors that shaped the experiences of an HIV diagnosis among a group of 15 Mexican American women in San Antonio, Texas in understanding how they seek help and how they make meaning of their HIV status.

Research Question(s)

This qualitative study explored how Mexican American women cope and make meaning of living with HIV by addressing the following questions:

(1) How have you lived with HIV?

(2) Who are those people or systems that support you in living with HIV?

(3) What role has the *Mujeres* support group played in your life?

(4) What are the major factors that influence you in your daily living with HIV?

In this chapter, I provide some background on the significance and magnitude of the AIDS epidemic. This includes a closer look at the prevalence rates and the groups that are most affected. A discussion on treatment disparities and how these impact communities of color is included. Some gender-related factors are introduced as well as how racial and ethnic minorities are impacted. This lays the groundwork for introducing

the population that this researcher focuses on, Mexican American women living with HIV, and leads into the literature review in the next chapter.

Background and Significance of the Study

HIV Defined

Despite the fact that June 5, 2011 will mark the 30th year of when AIDS was first identified, many remain uninformed and uneducated as to what HIV and AIDS means and the impact this disease has had on our society. HIV (Human Immunodeficiency Virus) is the virus that infects and destroys CD4 T cells (T4 lymphocytes) in the immune system. It is the virus that causes AIDS (Acquired Immune Deficiency Syndrome), a disease that weakens the immune system, making the body vulnerable to other diseases. It is caused by infection with the HIV, which is transmitted via blood and bodily secretions (Arretiere, 2006).

The number of people affected by this disease has reached pandemic proportions. HIV/AIDS is one of the deadliest epidemics in human history (CDC, 2006). Through 2007, more than 576,000 people with AIDS in the U.S. have died since the epidemic began (Hall, Song, & Rhodes, 2008). AIDS was unfathomable in 1981, when the U.S. Centers for Disease Control published its now famous report describing the deaths of five gay men in Los Angeles from a rare form of pneumonia. The lethal new virus that

terrorized the U.S. gay community that summer has since transformed the world, our culture and our lives (Jefferson, 2006). Acquired Immune Deficiency Syndrome (AIDS) has killed more than 25 million people since 1981, more than four Holocausts or twenty-two genocides in Rwanda (Arretiere, 2006).

Use of Terms

In addition to dearth of research on Latinos, another problem lies in the use of terms like "Hispanic" and "Latino" as umbrella terms that are applied across the board to groups with distinct historical, political, economic, and racial differences. Unfortunately, most health data, including the data on AIDS cases, use the term "Hispanic" and do not distinguish among Hispanic subgroups (Amaro, 1988) Specifically, Latinos represent a diverse population group comprised of Mexican Americans, Puerto Ricans, Central and South Americans and Cubans. The remaining 7% consider themselves to be Spanish-Mexican-Indians who live almost exclusively in the Southwestern U.S. (Maldonado, 1998). The term Mexican American is the most widely used and preferred term among members of this group when referring to themselves (Garcia, 1981; Smart & Smart, 1991; Reimann, Talavera, Salmon, Nunez & Velasquez, 2004). Due to the interchangeable use of Hispanic and Latino, this researcher will use the term that was used in the source or citation being referenced. When referring to the women in the study, the term Mexican American will be used. When making a general reference to women who are from Latino origin, the term Latina will be used.

When using terms like "*people of color*," "*women of color*," "*communities of color,*" this researcher is referring to people that are African American, Latino, Native American and Asian Pacific Islanders. (Please refer to the Glossary for a list of terms and acronyms used throughout the dissertation).

Prevalence Rates

Although this dissertation focuses on Mexican American women living with HIV, a clear picture of how other trends exist with particular sub-populations that are also strongly affected by HIV/AIDS is needed. Prevalence rates have increased in women, specifically *women of color*, young adults, MSM (*Men who have Sex with Men*), specifically *men of color,* and People over 50 (CDC, 2005). The following section will describe these three groups in more detail that have the highest HIV infection rate. It is important to review the other two groups to show the need for an increase in funding to allow communities to develop prevention efforts to raise awareness through education. Additionally, future research should examine the coping strategies unique to each of these groups. Are their coping strategies different than those found in Mexican American women living with HIV? Are there similarities in the way they make meaning of their HIV diagnosis?

Worldwide, approximately 40 million people are living with HIV/AIDS. Women today comprise half of all infections worldwide. For a variety of biological and socioeconomic reasons, women, especially young women, are at increased risk of

infection compared to their male counterparts (amfAR, 2006). The virus is transmitted more efficiently from men to women during sexual intercourse (NIAID, 2004) due to the female anatomy. The HIV Cost and Services Utilization Study (HCSUS), the only nationally representative study of people with HIV/AIDS receiving regular or ongoing medical care for HIV infection, found that women with HIV were disproportionately low-income. Nearly two-thirds (64%) had annual incomes below $10,000 compared to 41% of men (Bozzette S. A. et al., 1998). With half of all new infections occurring in people under 25, a whole new generation of young people is now in the crosshairs of the pandemic (amfAR, 2006).

Although men continue to represent the majority of new HIV infections and AIDS cases in the U.S., women account for a growing share. The AIDS epidemic in some states is more likely to have a woman's face. Almost a third of those estimated to be living with AIDS in New Jersey, Maryland, Connecticut, Delaware and the Virgin Islands are female (compared to 23% nationally). The concentration of new AIDS cases, as measured by AIDS case rate per 100,000, is highest in the Northeast and South. Seven of the ten states with the highest case rates among women are in the South, with Washington, DC, topping the list at 113.3 per 100,000 or twelve times the national rate among women (Kaiser, 2006).

Other sub-populations remain at increased risk. MSM account for approximately 45% of newly reported HIV/AIDS diagnoses and nearly 54% of cumulative AIDS diagnoses (CDC, 2004). A recent survey indicated that in several large U.S. cities,

approximately one in four MSM surveyed in social venues is infected with HIV, and nearly 50% of MSM are unaware of their HIV infections (CDC, 2005). Moreover, young MSM were least likely to know they were infected, and MSM from racial/ethnic minority populations consistently demonstrated higher prevalence than white MSM. Annual incidence among MSM is high, ranging from 1.2% to 8.0% (Fenton & Valdeserri, 2006).

A growing number of older people in the U.S. are being diagnosed with HIV. Many are becoming infected because they don't even realize how great they are at risk. It is thought that older people may lack awareness of the risk factor for getting HIV (Graham, 2004). The number of AIDS cases reported in adults 50 years and over quintupled between 1990 and 2001 from 16,288 to 90,513. As a result, the number of HIV-infected persons over 65 has grown ten-fold in the past 10 years. Occult HIV infection is a problem in older adults, because physicians are less likely to ask older patients about high risk sexual activity or injection drug use because of social norms (Gebo, 2004).

As illustrated, a number of sub-populations are being impacted by HIV/AIDS. However, women, MSM, and people over 50 are reported as the three main groups that are being impacted at greater levels as well as the ones that are going undiagnosed due to individuals not being aware of their risks or simply not having the education to recognize their own risk factors.

HIV/AIDS and Racial and Ethnic Minorities

Twenty-five years after the virus was first documented in gay white men, HIV has increasingly become a *disease of color*, with blacks bearing the heaviest burden by far. African-Americans make up just 13% of the U.S. population, but account for an astounding 51% of new HIV diagnoses. Black men are diagnosed at more than seven times the rate of white men, black females at 20 times the rate of white women (Jefferson, 2006). Although Latinos represent approximately 14% of the U.S. population, they account for 19% of the AIDS cases diagnosed in 2005 and 16% of the AIDS cases diagnosed since the start of the epidemic. Latinos account for 18% of HIV/AIDS cases diagnosed in 2005 in the 33 states with confidential names-based reporting (Kaiser, 2006). In addition, AIDS-related illnesses represent the fourth leading cause of death among Latinos ages 25-44, according to CDC (Kaiser, 2004).

Over the past decade, the epidemic has increased most dramatically among women of color, namely Black and Latina. Women of color are disproportionately affected by HIV/AIDS. The following statistics will help reveal just how critical this crisis is for these two groups of minority women.

AIDS is the number one killer of African American women ages 25 to 44 (NIAID, 1997). African American women accounted for 67% of estimated female AIDS cases in 2004, but only 13% of the U.S. female population. In 2004, the case rate for African American women was 48.2 per 100,000 or 23 times higher than the rate for white women (2.1). Among women, the number of HIV-related deaths and HIV death rates are

highest for Black women. In 2006, HIV was the third leading cause of death among Black women ages 25-34, compared to the fifth leading cause for women overall in the U.S. (Kaiser, 2010). It is important to reflect on the disproportionate number of cases of HIV/AIDS among African American women as they are the group that leads the nation in this epidemic. There is a fear that the number of new HIV cases among Latinas will begin to mirror that of their African American sisters if something is not done to stop the spread of this disease. It also helps to share the lessons learned from this community while conducting research with another *community of color*. By doing so, this may offer opportunities for future research in comparing Black women and Latinas in exploring how each group copes and makes meaning of their HIV diagnosis.

HIV/AIDS among Latinas should not be overlooked simply because it is less prevalent compared to African American women. While Hispanic/Latino women represented a quarter (24%) of new infections among Hispanics/Latinos in 2006, their rate of HIV infection was nearly four times that of white women (CDC, 2008). Many of these Latinas are middle-aged and were infected by their husbands or boyfriends who are bisexual or intravenous drug users. Poverty, traditional gender-role beliefs, sexual coercion, sexual abuse, and difficulties talking about sex may all contribute to these rates (Marin, 2002 & 2003).

Due to the continued high rates of HIV and other STIs which disproportionately impact African-Americans and Latinos in the South, a group of HIV/AIDS directors representing fourteen southern states came together to develop the Southern States

Manifesto at a meeting held in Nashville, Tennessee in June, 2002. They were charged with discussing the unique and critical challenges shared among the southern states and to develop a corrective action plan. The need for this call to action is evidence enough that an emergency is underway in the southern U.S. states. In fact, many factors contribute to barriers in providing prevention and care services in the South. According to the classic Southern States Manifesto published in 2003, *people of color* in the South face numerous barriers:

- Insufficient service delivery systems for African-American and Latino men who have sex with men (MSM) due to the lack of evidence-based interventions for non-identifying African-American and Latino MSM, especially in rural areas.
- Distrust of the health care system and its ability to protect confidentiality of individuals infected with HIV or STIs.
- Inadequate community-level programming to address the stigma associated with HIV and STI disease.
- Scarcity of faith-based initiatives providing prevention and care services in the conservative and religious climate of the South.
- Need for culturally competent and culturally sensitive programming.
- Limited organized community-based advocacy in order to promote capacity building among African-American and Latino focused agencies.
- Continued denial of HIV status by infected individuals until symptoms are evident.

- Limited access to health care facilities due to inadequate transportation, insufficient child care, under insurance or no insurance, overburdened care system and poverty.

Pfizer, Inc. and The Pfizer Foundation's charitable giving programs provide grants for initiatives focused primarily on health care and science education. The impetus for this philanthropic effort was a direct result of the findings that are shown in the Southern States Manifesto. As stated in their website, although the number of new cases has declined or leveled off across most of the United States, the number of new AIDS cases in the South continues to rise (Pfizer, 2006).

Others such as Reif, Geonnotti, & Whetten (2006) have examined the high number of cases found in the South as compared to other regions in the U.S. Though only 36 percent of the U.S. population lives in the region, about half of people living with HIV or AIDS in the US live in the South (Reif, Geonnotti & Whetten, 2006). The Obama Administration's National AIDS Strategy acknowledges this problem and declares an intention to rectify it, but changes in federal policy alone will not impede the spread of the disease (Southern Exposure, 2010).

In contrast, other U.S. regions are experiencing stable rates or small increases in new AIDS cases. Furthermore, the AIDS epidemic in the Deep South is more concentrated than in other regions among African Americans, women, and rural residents. The Deep South also has some of the highest levels of poverty and uninsured individuals, factors that complicate the prevention and treatment of HIV infection. Further research is

needed to determine the cause of the disproportionate rise in AIDS incidence and to develop effective means of preventing HIV infection and caring for those infected in this region (Reif et al., 2006). The Deep South is a descriptive category of the cultural and geographic sub-regions in the American South. The Deep South was also commonly referred to as the Lower South or the "Cotton States." Some sources define the Deep South as all or part of those states which made up the Confederacy. In addition to South Carolina, Mississippi, Alabama, Georgia, and Louisiana, it includes Texas, Florida, Arkansas, North Carolina, Virginia, and Tennessee (Wikipedia).

It is important to note that there are emerging Latino communities in the Deep South as a result of unique intersection of migration patterns and economic opportunity within the last several decades. Increasingly, Latinos are becoming an important component of the social and economic fabric of the Deep South. However, with all these strides, Latinos continue to be underrepresented in important services, such as public health, and in particular within the realms of HIV prevention and capacity building provision. This trend becomes more disturbing as the rates of HIV infection for Latinos continue to rise (Latino Commission on AIDS).

The South has fewer large metropolitan centers than other parts of the country, with a larger proportion of its population living in rural areas. This results in a shortage of high quality health care personnel because professionals often choose to practice in large cities. The scarcity of qualified providers is especially acute in rural areas, where transportation to care can be a major service barrier. In addition, southern states continue

to experience problems often encountered when serving vulnerable populations in a less than adequately funded environment (Southern States Manifesto, 2003). By 2001, 46% of newly diagnosed cases of AIDS were located in the South. More people have AIDS in the South than in any other U.S. region, according to the Henry J. Kaiser Family Foundation (Graham, 2004). Despite these growing numbers, southern states have historically received less federal funding for HIV/AIDS care and prevention. It has been estimated that a special appropriation of nearly $122 million would be needed just to offset this disparity, should other funding levels remain the same (Southern States Manifesto, 2003).

Reduced access to health care is associated with disadvantaged socioeconomic status and cultural and language barriers that limit access to prevention information and other health services (U. S. Public Health Service's Office on Women's Health, 1998). Poverty can be used as the all encompassing principle that explains why socioeconomic factors have an effect on disease progression and survival of women living with HIV/AIDS. On average, women are diagnosed with HIV and enter clinical care at a later stage of their infection than men, and are less likely to receive antiretroviral therapy, and may receive less timely diagnoses of opportunistic infections" (Marte, 1998). Historically, inequalities in wealth have manifested themselves as inequalities in morbidity and mortality. If poverty and its serious physical, social, and emotional health consequences are to be overcome, some level of effective economic redistribution, or at least the ability to access the things that money can buy, including health care, is

necessary (Angel, Lein, & Henrici, 2006). Until then, a health crisis continues in our country that makes certain populations more vulnerable for health problems. The issue of poverty was explored as a barrier for Mexican American women living with HIV in San Antonio. The majority of study participants were in fact found to meet the poverty guidelines which will be further explained in the Chapter 5. Furthermore, these findings are instrumental in discovering the way in which the study participants make meaning of their diagnosis. Does poverty affect the way they cope?

Treatment Disparities

Many racial disparities are evident in the fight to prevent new AIDS cases among women of color. Although statistics show the large number on new HIV cases in rural Southern states, there are many women that are disproportionately affected that live in urban areas as well. Infected minority women tend to be poor, young residents of urban areas, particularly in the Northeast and the South. The disproportionate concentration of HIV/AIDS among women of color and those with limited resources, as well as the epidemic's impact on younger women, are especially striking. Given these trends, efforts to stem the tide of the U.S. HIV/AIDS epidemic will increasingly depend on how and to what extent its effect on women and girls is addressed (Kaiser, 2006).

Minorities are less likely to have health coverage than Whites. At every income level, Hispanics are less likely to be insured than other racial/ethnic groups (HRSA, 1999). According to Congresswoman Lillian Roybal-Allard, Chair of the Congressional

Hispanic Caucus, across all income levels, Latinos consistently have the highest rate of being uninsured. In fact, 22 percent of the forty-one million uninsured people in 1996 were Latinos (NMAC, 1999). The South is home to the greatest numbers of uninsured persons, an estimated 17 million (Coverage Matters: Insurance and Health Care, 2001 & Graham, 2004). Latinos and African Americans are most at risk of being uninsured. Nearly one-half of working-age Latinos (46%) lack health insurance, as do one-third of African-Americans (Collins, 2002). Although race and ethnicity are not risk factors for HIV/AIDS, they are markers for other factors that put people at increased risk, such as lack of health insurance and limited access to care, according to Paul Denning, M. D., epidemiologist from the Centers for Disease Control and Prevention (Greeley, 1995).

Cultural Issues & Need for Cultural Competence

Hispanics are the largest ethnic minority population in the United States, and they are under-served by the health-care system. Hispanics are less likely to seek and receive health-care services, which might contribute to their poorer health status and higher rates of morbidity and mortality (CDC, 2004). Access to care is one of the major barriers that Mexican Americans face in large part due to discrimination as well as lack of health insurance. Racism experienced by Latinos is often dismissed or is not taken as seriously because race and racism continues to be understood as a Black/White issue. Prejudice against Latinos, particularly Spanish speakers and immigrants, continues to fuel discriminatory practices that complicate access and add stress to the lives of many Latinos already burdened by a host of social and health problems (Shedin, M. G. &

Shulman, L. C., 2002). Some Latinos continue to be suspicious and mistrustful of government and large organizations. This serves as another cultural barrier that needs to be explored when addressing the needs of Mexican American women living with HIV. There is a scarcity of bilingual/bicultural providers to make Latinos comfortable in seeking care and treatment services. In addition, for Latinos who are less acculturated or less familiar with the health care system, access to care and services is enhanced if the individuals have a core service provider who is trusted to act in the individual's best interest (Multhoma County Health Department, 2001). The issue of racism was explored in this study to determine if this has impacted the lives of Mexican American women living with HIV and how they cope and make meaning of their diagnosis.

Despite the rising numbers, there are still few studies that address the specific cultural issues related to sub-populations, such as Mexican American women in the Southwest and it is imperative for this group as well as others to be studied and conducted by culturally-competent researchers. Developing cultural competence with Latino patients requires a close look at the cultural and personal characteristics that the patient brings to the encounter. The cultural traits may be known, but the unique personal issues, closely linked to culture but specific of each individual's life experience, must also be identified (Chong, 2002). From a social worker's perspective, cultural competence is defined as the set of knowledge and skills that a social worker must develop in order to be effective with multicultural clients. The culturally competent

person has the task of bringing together elements from his or her culture of origin and the dominant culture to accomplish bicultural integration and competency (Lum, 1999).

Research on Latinas and HIV

The dearth of basic and applied research with Hispanics, in general, is particularly striking given that Hispanics constitute the second largest minority group in the United States and are the fastest growing ethnic minority (Padilla & Salgado de Snyder, 1985). The United States has the fifth largest population of Latinos in the world, following Mexico, Spain, Argentina, and Colombia. Latinos are the fastest growing major population in the United States. Since the turn of the century, Hispanics have accounted for more than half (50.5%) of the overall population growth in the United States -- a significant new demographic milestone for the nation's largest minority group. From April 1, 2000, to July 1, 2007, the Hispanic population grew by 10.2 million to 45.5 million, an increase of 29%. During this same period, the much larger non-Hispanic population of the U.S. grew by 10 million, an increase of just 4%. As of mid-2007, Hispanics made up 15.1% of the total U.S. population but accounted for a majority of the nation's total population growth since 2000 (Fry, 2008).

The few studies of Mexican American women and other women of color living with HIV focus more on modes of transmission and demographics rather than on psychological or psychosocial issues. This lack of research parallels neglect of women of color in general. In a call to action report published by the Hispanic Federation, Elsa

Rios' piece entitled, "*Las Olvidadas"* (The Forgotten Ones) states that Latinas remain virtually ignored by health policy makers and are one of the most under-served HIV-affected populations. She goes on to say that such neglect has been the unacceptable loss of many Latina lives that have left Latino families and communities fractured and vulnerable (Rios, 2006).

Psychosocial Issues

While the number of women diagnosed with AIDS is doubling every one to two years, little is known about the psychological and behavioral factors influencing the transmission of HIV in women, the majority of whom are impoverished and socially disadvantaged (Ickovics & Rodin, 1992). It has proved difficult to identify many of the women at risk for HIV and to provide appropriate education, counseling, and HIV testing services at the many sites where women traditionally receive medical and social services (O'Leary & Jemmott, 1996).

Support groups are but one form of mental health intervention available to reduce emotional stress related to HIV and to increase the level of coping. Not all Mexican Americans are comfortable with this type of intervention. Women raised in different cultures may need other models of support, such as incorporation of family and community networks (McDonald, 1989). This speculation is supported by quantitative and qualitative research (Arches 1997; Asbury, 1987) that reveals that members of minority cultures tend to reach out for help from their families and kinship networks

(which may be defined differently than mainstream society traditionally defines it) before utilizing service agencies. It is important to examine the ways that Mexican American women living with HIV cope and their approaches in seeking help.

Research Gaps

The increasing cultural diversity among professional social workers and the clients they serve has resulted in the need to critically examine some of the earlier notions about the epistemology, ontology, and methodology of social work research and practice. One outcome of these analyses about how and by whom research projects are carried out is the emergence of "native," "indigenous," or "insider" research in which scholars conduct studies with populations and communities and identity groups of which they are also members (Kanuha, 2000). Sudbury illustrates her commitment to producing a study which was useful to the population she studied, Black women, stating her intentions of treating the women she was researching in an ethical manner, that she remain objective, that she place her understanding of the intersection of race, gender, and class at the center of her research analysis and finally that she engage in the movement and participate in an organization as a "sister in the struggle" (Sudbury, 1998).

Reflective Section

I have worked in the field of HIV/AIDS in a variety of capacities since 1988 to 2009 ranging from social worker to activist to administrator, for a total of twenty-two years.

I began my career as a frontline social worker and member of a multidisciplinary team serving pediatric HIV/AIDS patients and their families in a clinical setting. I later moved on to work with the adult population for the Bexar County Hospital District known as the University Health System in San Antonio, Texas. For over fourteen years, I served as Founder and Executive Director of Mujeres Unidas Contra el SIDA (Women United Against AIDS), the only women-centered and Latina-operated AIDS Service Organization (ASO) in San Antonio, Texas and South Texas. Through my work I witnessed the changing trends in the faces of AIDS and had first-hand experience in exploring effective strategies for reaching communities of color through prevention messages. I worked to develop adequate support services that are culturally and linguistically appropriate for Latinos. Although I have been aware of the growing numbers of new HIV and AIDS cases affecting women, especially women of color, never before have the numbers reached such high proportions.

As one of the few social work professionals who has provided services to people living with HIV/AIDS in my local community, I came to realize the need for all social

workers to better understand the unique needs of all individuals living with HIV, but most especially to the population that is targeted by Mujeres Unidas- -Mexican American women whose lives are impacted by this illness.

One of the many lessons I learned from having devoted the majority of my professional social work career to working with Mexican American women whose lives have been affected by HIV/AIDS, is the need to pay close attention to key cultural factors. One example is language. When delivering any kind of service to Mexican Americans, one should be cognizant of the fact that bilingual/bicultural staff is needed to work with this population in order to avoid a potential language barrier.

Cultural implications are necessary to consider in understanding Mexican American women's unique needs and the choices they make regarding their treatment and the type of care they seek. It was striking to learn the different ways that Mexican American women display their coping mechanisms after learning of their HIV diagnosis. I have observed that women of Mexican origin will always put others' needs before their own, especially when it comes to their children. I further noted that they tend to display a great deal of respect for people in authority, especially in a medical setting. This may result in a reluctance to ask for help, which can potentially lead to taking their medications incorrectly or not fully understanding medical advice regarding their treatment. Through this research, I have explored the experiences of Mexican American women who are living with HIV. Specifically, this study focused on how they cope with and make meaning of their HIV experience.

As the researcher of this dissertation, I strongly believe I have taken a similar approach to Sudbury when conducting this qualitative study.

Chapter Two

Literature Review

This literature review illustrates how this epidemic has evolved over time by discussing a historical timeline and tying it to the specific needs of women, more specifically, Mexican American women living with HIV. This historical account of the 25 years of AIDS examines the trends of the epidemic, the increase in cases of women and the ways women have had to cope with their experience with HIV. It is important to examine how Mexican American women access healthcare and especially when and how they seek mental health services outside of their family and how they find the strength and resilience to cope with their daily struggles. Cultural factors influence the risks of acquiring HIV specific to Mexican American women and the coping strategies they use. The theories of resiliency and coping will be reviewed in defining ways that Mexican American women living with HIV cope and make meaning of their diagnosis. Issues of race, class and gender are infused throughout this dissertation in order to determine if these factors play a role in how Mexican American women whose lives are impacted by HIV cope and make meaning of their experience. Because the single largest Latino ethnic group is Mexican representing 60% of the Latino population, followed by Puerto Ricans (15%) (US Census, 2002) it is important to explain that with the rising number of HIV cases among women in the South, that many women living in this region are Mexican American and/or of Mexican descent. It is also important to note that immigration issues may affect those individuals that are undocumented, which in turn can

impact their ability to seek proper care. Due to the close proximity to the US/Mexico border, some of these issues may impact people with HIV living in San Antonio.

As mentioned in Chapter 1, *women of color* Black, Latina, Asian American, and Native American constitute a large proportion of most social work caseloads but their unique needs are often left out of in the social work literature (Gutierrez, 1990). For this reason, there needs to be an emphasis on how to better prepare social workers to address the needs of these Mexican American women and their families as potential clients.

Through the time line presented below, the reader will better understand women's situation at this time of the AIDS pandemic. It is necessary to step back into time and closely examine and highlight those historical events that have taken place in the 25 years of AIDS in order to gain a clearer picture and understand why certain under-served communities, i.e. Latinas are currently disproportionately affected by HIV/AIDS (CDC, 2005**).**

A Historical Timeline

The pandemic dates back to 1980 when the first cases of two rare illnesses *Pneumocystis Carini* Pneumonia (PCP) and Kaposis Sarcoma (KS-- a rare form of cancer-- were reported in New York and California (Shilts, 1987). In 1981, The Centers for Disease Control and Prevention (CDC) published the first report on what would become the AIDS epidemic in its weekly *Morbidity and Mortality Weekly Report*, (Gottlieb, 1981).

Originally the virus was called GRID (Gay Related Immune Deficiency) and was also referred to as the "gay plague" (Feldman & Miller, 1998). Other names given to the syndrome were "gay cancer" and "new pneumonia" until the name of Acquired Immune Deficiency Syndrome (AIDS) became the worldwide recognized name (Wolf, 2002). Since the early days of this epidemic, women's needs have been greatly ignored. In 1982, the National Institute of Health rejected a proposal for a research study to determine whether women get AIDS (*Mortality and Morbidity Weekly Report*, 1982). Shortly after, in 1983, the first case of AIDS in a woman was identified in San Francisco (Wolf, 2002). In 1986, three years later, women living with HIV/AIDS in New York City came together to form the Women and AIDS Resource Network (WARN), (Wilder, 2002).

It took Congress ten years from the time of the first reported cases to pass a law (Public Law 101-381) that would address the needs of people living with HIV/AIDS and offer hope to those who had no other means of accessing HIV specific medical care. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was originally written to cover a five-year period, with the option of reauthorization at the end of that time. However, each year, funding levels for the act's programs have to be set as part of the annual Congressional budget process, and each year, the exact amount of funding available through its programs has varied (Kaiser, 2003).

Each year, advocacy groups around the country work hard to convince legislators to increase funding allocations to support HIV/AIDS programs at the time they consider

reauthorization of the CARE Act. Typically, women and children are low priorities in funding allocations despite the fact that the number of new infection of female cases is rapidly growing. It is important to note that the CARE ACT is named after an HIV positive teenager, Ryan White who became a national spokesperson for AIDS education, treatment, and funding and testified before the President's Commission on AIDS in 1988 during the Reagan Administration (White, 1991). Historical evidence makes it clear that women's specific needs and concerns have been greatly ignored. The void is even greater for Mexican-American women.

During the Reagan Administration, advocacy groups and coalitions formed as HIV/AIDS spread in our country and discrimination against people living with HIV/AIDS became more pronounced, increasing the stigma of having an AIDS diagnosis. In fact, as part of a larger study of racial/ethnic variations in access to HIV pharmaceuticals, researchers at the AIDS Policy Research Center and Institute for Health Policy Studies, University of California-San Francisco used a rapid assessment approach to gather data on social, psychological, and cultural factors that influence access to HIV therapies. This research team interviewed a racially diverse mix of HIV-positive patients at four clinics in San Francisco and Oakland and found that the number one access barrier identified among African Americans, Latinos, Native Americans and Asian/Pacific Islanders was stigma associated with HIV disease (ACT UP, 2003).

Two groups that have been pioneers in the fight against discrimination and stigma are the AIDS activist group, ACT UP (the AIDS Coalition to Unleash Power), founded

by Larry Kramer in New York City, and the National Minority AIDS Council, established in Washington, D.C. to address disparities and the needs of people and communities of color living with and affected by HIV/AIDS. Both groups exist today though they are among the number of ASOs struggling to stay afloat, mainly due to funding issues. Few documents like to Southern States Manifesto have been published. Although some efforts have been made to advocate for communities of color, the emphasis in relation to Latinos is more focused on MSM or on disparities related to socioeconomic disadvantages for Latinos as a whole. There is no mention of Latina issues in particular.

The first document that even came close to examining Latina issues is found in the Hispanic Federation's Call to Action, written by Elsa Rios and published in 2006. The mere title of the document, *Las Olvidadas,* speaks for itself. Translated into English the title reads: "The Forgotten Ones" as this is the sentiment of community activist and advocate Elsa Rios as well as others who have worked tirelessly to bring the needs of Latinas with HIV/AIDS to light. So, although ACT UP and NMAC have made great strides in advocating for *communities of color,* much work remains to be done in addressing the Latina agenda. The only way strides that can be made in creating effective advocacy strategies for Latinas living with HIV/AIDS as a supportive measure is to give these women voice when examining research questions that relate to what support systems are used to cope and make meaning of living with HIV. Once this is determined, then programs can become better established in a culturally competent way.

In 1998, The Secretary of Health and Human Services declared AIDS an ongoing and severe crisis in African American and Hispanic communities in the United States and encouraged Congress and the Administration to respond to the growing epidemic in these under-served areas (CDC, 2003). In direct response to this, the Congressional Black Caucus Congress funded the Minority HIV/AIDS Initiative (MHAI) which was designed to directly target increased funding, capacity building services, and technical assistance to respond to the growing needs in minority communities (OMH, 2003). Soon after the Southern States' AIDS/STD Directors Work Group formed in collaboration with the National Alliance of State and Territorial AIDS Directors to seek the appropriated funding to develop and author the Southern States Manifesto HIV/AIDS & STDs in the South. A Call to Action addressed the unique epidemics of HIV/AIDS and STDs in the South and their disparate impact on southern citizens. Seven of the ten states with the highest case rates among women are in the South (Kaiser, 2006). According to the Southern States Manifesto, 40% of the people estimated to be living with AIDS reside in the South and 46% of the estimated new HIV/AIDS cases have been reported in the region since 2001. According to the CDC figures cited in the Manifesto, more than 130,000 people in the South have AIDS, compared to about 100,000 in the Northeast, 36,000 in the Midwest and 62,000 in the West (Kaiser, 2002).

The Southern States Manifesto was published in March 2003 and includes Texas as one of the Southern states under crisis. When addressing the need for equal access to medications, the authors of the Southern States Manifesto state: "It is unacceptable,

counter productive and contrary to the vision of a compassionate society for anyone in this country to be unable to obtain, on a regular and guaranteed basis, medications that improve and prolong their lives, facilitate their positive contributions to family and the economy and help to reduce the further spread of this pandemic" (Southern States Manifesto, 2003). Unfortunately, many women of color who find themselves in impoverished conditions continue to be denied equal access to medications and treatment. One study found that women with HIV were less likely to receive combination therapy and fared more poorly on other access measures than men (Shapiro et al., 1999). This information was explored in the interviews with Mexican American women living with HIV. Specifically, the demographic data illustrated the relationship to income status and access to health care and the findings clearly showed the number of women living in poverty and their poor health coverage.

Increased Cases of Women with HIV

It is important to revisit the number of women living with HIV/AIDS in the U.S. even though it has been previously highlighted in Chapter One in order to emphasize the increasing number of cases among Latinas. It is of particular importance when examining how Mexican American women in San Antonio cope and make meaning of their HIV diagnosis. The AIDS epidemic's impact on women has become more pronounced over time, with women comprising an increasing share of new AIDS cases reported each year. The proportion of new AIDS cases reported among women has more than tripled since the mid-1980s, rising from 7% in 1986 to 26% in 2001 (Kaiser, 2003).

In 2006, there were 15,000 new HIV infections and, in 2008, there were 9,813 AIDS diagnoses among women (Kaiser, 2010). Currently, women comprise half of all infections worldwide (amFAR, 2006).

Women and HIV

Latinas and HIV

AIDS has hit Latinas especially hard. Latinas' infection rate as a proportion of all Latino AIDS cases has climbed from 15% in 1990 to 23% in 2002 (Ruiz et al., 2003). This change represents 53% increase in the number of Latinas with AIDS since 1990. Latinas account for 17% of estimated AIDS diagnoses, compared to 13% of the female population ages 13 and over (Kaiser, 2010). Despite these facts, Latinas are one of the most under-served HIV-affected populations (Rios, 2006).

While the number of women diagnosed with AIDS has doubled every one to two years, little is known about the psychological and behavioral factors influencing the transmission of HIV in women, the majority of whom are impoverished and socially disadvantaged (Ickovics & Rodin, 1992). More research is needed to identify the psychological issues related to the transmission of HIV and to understand ways in which prevention messages can reach this population. It has proved difficult to identify many of the women at risk for HIV and to provide appropriate education, counseling, and HIV testing services at the many sites where women traditionally receive medical and social services (O'Leary & Jemmott, 1996). This may be in part due to the continued stigma associated with HIV/AIDS as well as the possible mistrust on the part of members of

communities of color that still exist because of past negative experiences with traditional health seeking institutions. Therefore, the need for non-traditional interventions and approaches in reaching women, especially women of color is evident. If there is an overall lack of research for women in general, there is more of a scarcity of research for Latinas and other women of color. According to Laura Echegaray, a Latino Disability Educator at the Independent Living Resource Center in San Francisco, the most important means of outreach to Latinos with disabilities is to "meet them where they are." She states: "When I say meet them, I don't just mean physically, but also where they are mentally. We need bilingual communication. A Spanish line is as much access as a ramp. If you have to deal with a phone without Spanish…that is a barrier" (Echegaray, 2002).

Health Care Seeking Behavior Among Latinos

Researchers have explored the processes by which help is sought following a determination on the part of the client to seek help. Kleinman (1980) found in his study of patients, illness, and health care in Taiwan that various enabling factors played an important role in the decision to seek health care and the form of that care. The family's socioeconomic status, orientation to Western or traditional values, and past experiences with health care; the geographic nature (rural or urban) of the setting; and the patient's proximity to specific treatment resources were all found to be important factors (Loue, 2000). Padilla & Keefe (1984) reported that four factors determine the selection of a source of help when Mexican Americans face emotional problems: (1) perceived nature

of the problem, (2) perceived qualities of the source of help, (3) language ability and preference, and (4) characteristics of the social network, especially family members. They go on to discuss the importance of the role of family members in the culture of Mexican-Americans. Nilda Chong, author of The Latino Patient: A Cultural Guide for Health Care Providers, does an excellent job in summarizing the principles of cultural competence that every health care provider who serves Latino patients should understand. She describes factors that may impact the decision to seek health care, such as language, health insurance coverage, and acculturation. Access to health care means having the timely use of personal health services to achieve the best health outcomes (Milliman, 1993).

Issues Impacting Access to Care

Quality health care requires that patients and providers communicate effectively. Language is a barrier to quality health care for many racial and ethnic minorities. About 47 million Americans or 18% of the population spoke a language other than English at home in 2000, up from 32 million in 1990. Of those individuals, 28 million (about 11% of the population) spoke Spanish (National Health Disparities Report, 2005). A 2010 report by the U.S. Census Bureau highlights two trends in the United States population with implications for social policy.1 First, the number of United States residents aged 5 years and older who speak a language other than English at home has more than doubled since 1980. The number of individuals who spoke a language other than English at home

increased 140 percent from approximately 23.1 million in 1980 to 55.4 million in 2007. Spanish speakers account for the largest share of the population who spoke a language other than English at home in 2007 (62 percent). By 2007 the number of Spanish speakers had grown by more than 23.4 million (National Center for Children in Poverty, 2010). If a provider speaks the native language of the client/patient it will make it easier for that individual to express his/her needs and concerns.

Health insurance facilitates entry into the healthcare system. The uninsured report more problems getting care, are diagnosed at later disease stages, and get less therapeutic care. They are sicker when hospitalized and more likely to die during their stay (Hadley, 2003). Lack of insurance continues to be a problem in America, but tends to have a greater affect on some communities in particular. Latinos are more likely to be uninsured than other Americans because they are employed in the low-skill and low-paid sectors of the economy that are less likely to provide insurance coverage to their employees as a benefit. A contributing factor is that programs such as Medicaid offer limited coverage to the unemployed but not to the working poor. Consequently, Latinos have less access to preventive and primary health care (NCLR, 2005). During the 1990s, despite the fact that the economy was growing, the number of uninsured increased by about a million a year. The number of non-elderly uninsured grew by 800,000 in 2004, for a total of 6 million more uninsured since 2000 (Kaiser, 2005). Although Latinos are the most highly employed minority and almost two-thirds have health insurance coverage, more than one-third lack basic coverage (Southern States Manifesto, 2003).

Latinos who have immigrated to the United States, acculturate in certain ways in order to adapt to a new culture. For Latino immigrants, these changes include learning to live in an environment that is saturated with rules and regulations. Habits that are second nature for Americans, such as taking a number, waiting in line, filling out forms, and so on, can be a nightmare for Latinos (Chong, 2002). Acculturation involves different levels of destruction, survival, domination, resistance, modification, and adaptation of native cultures following interethnic contact (Berry, 2003). Berry conceptualizes acculturation as occurring in strategies such as, assimilation, marginalization, separation, and integration where individuals make determinations about maintaining cultural characteristics and the amount of contact needed with dominant group members to obtain a suitable means of adaptation. Research on acculturation indicates that individuals unable to reconcile these cultural changes often experience acculturative stress resulting in reduced mental heath outcomes among some groups (Berry, 2003; Ell & Castaneda, 1998; & Hovey, 2000). Some of these same issues of acculturation apply to second and third generation Latinos as they often possess cultural traits that have been passed on from generation to generation. Therefore, mental health outcomes among Mexican American women living with HIV warrants a closer look at their approach to seeking help outside their family. This will help to clarify what their own coping strategies are and how they make meaning of living with HIV which is usually accompanied by stigma and discrimination and other psychosocial issues that they encounter and will be explored throughout this study.

Cultural Issues Related to Oppression and HIV Transmission

While Latinas face issues similar to those faced by all women whose lives have been impacted by HIV/AIDS, there are additional factors that are culturally-specific to this population. Some of the issues discussed here are not applicable to all Latinas, since they vary depending on the level of acculturation, life-style, where they were born and where they live. Special emphasis is placed in this section on Mexican American women as this is the population that was specifically studied through this dissertation and is important as a growing population. This is directly related to the research question of how Mexican American women living with HIV cope and make meaning of their diagnosis and can help to clarify why some of these women seek outside intervention and some choose not to.

In her book, *Our Cry for Life: Feminist Theology from Latin America*, Maria Pilar Aquino, a leading Latin American feminist liberation theologian, gives her impression of the causes of oppression of women in Latin America. It is essential that the gender aspects of the oppression of women be an integral part of the theological reflection. She further argues that Marxist analysis of the oppression of the poor does not do justice to women's concerns. Women suffer not only from economic exploitation and socio-political and cultural oppression, but also from androcentric racial and sexual oppression (Aquino, 1993). Failure to recognize this, according to Aquino, leads to a tendency to

view women's subordinate condition as a non-fundamental, a non-central, or a secondary concern (Almazan, 2005).

Aquino addresses the centrality of daily life for the liberation of women. It is in women's daily life encounters that unequal relationships between men and women are produced and reinforced. Women experience this inequality in the home, the family, and in the way that men and women relate to one another in the arena of domestic life. She further argues that women confront male superiority, discrimination and sexism in their everyday life (Aquino, 1993).

Although her book focuses on women from Latin American, Aquino's analysis of the women's oppression can be applied to Latinas of the United States. For example, many Mexican and Mexican American women are often times not identified to be at risk for HIV because the identified risks factors reflect those of their male partners' and not their own. Women are often identified only after they are screened by asking questions that relate to their male sexual partner, such as, have you had sexual intercourse with Men who have Sex with Men or have you had sexual intercourse with a male partner who is using intravenous drugs? This was considered such a timely issue that a Women and AIDS Institute was held entitled, *The Neglected Truth About Women and AIDS: Women and AIDS Policy & Service Strategy Session* at the Staying Alive 2006 Summit on December 8, 2006 in New Orleans, LA. Until policies and recommendations are introduced that see women as individuals and are screened for their own risk, many women with HIV will continue to go undiagnosed. The Ms. Foundation for Women's

National Women and AIDS Collective has written and disseminated two policy recommendations that focus on the allocation of 25% of all Ryan White CARE Act funds across all titles to community-based organizations that currently and historically have been led by and for HIV-positive women (Ms. Foundation, 2006). If adopted, this practice would mark the beginning of efforts made to enable women to access the services they need and begin to eliminate disparities and to eradicate the oppression women living with HIV, especially women of color, experience.

Another example of oppression Mexican woman face concerns immigration status and its relation to permanency planning both for herself and for her children. Immigration status itself can change with an HIV diagnosis. Immigration law can require applicants for citizenship to take an HIV test. If the test is positive, citizenship is automatically denied. If an individual from Mexico is applying after marrying a U.S. Citizen, the same law applies and if that person is found to be positive and living in the United States, they are automatically deported to Mexico, regardless if the couple has consummated the marriage and have children. This has implications particularly for large numbers of Mexican nationals living in the Southwest, and San Antonio is one of the cities that attract large numbers of undocumented men and women from Mexico because of its close proximity to the U.S./Mexico border. An HIV positive Mexican immigrant who does not have permission to be in this country may have difficulty in accessing medical care and applying for entitlements. Immigrant women often work two jobs to send money to relatives in their homelands. Those who are not properly

documented cannot get insurance and are often paid illegal, low wages (Lynch, 2000). Some federally funded programs that assist with medical and drug assistance can no longer extend services to those who do not hold U.S. citizenship. This is an even more pressing issue with the Immigration Reform Bill that is currently being debated in our country and with the passage of the new immigration law enacted by our neighboring southwest state of Arizona.

Discrimination must be considered when discussing health care access for Latinas and other *people of color*. In the classic work of Gutierrez, she has established that women of color struggle with the double burden of racism and sexism, which exacts a toll on their mental health and restricts their opportunities (Gutierrez, 1990). As previously mentioned above, Latinas are disproportionately uninsured or often considered to be underinsured when seeking medical care. Latinas not only have the highest uninsured rate of women from any racial/ethnic group (37%) but the number of uninsured continues to rise (Kaiser, 2001). For non-English speakers, access to health care can be extremely difficult. Yet clinics serving Latinas often do not have bilingual medical providers and thus non-English speaking patients experience difficulty in understanding explanations about their condition and medications. Such discriminatory conditions only pose additional challenges to an already difficult situation in accessing medical care which may add more stress and raises the issue of coping strategies needed to live with HIV as a Mexican American or Mexican national.

It is not often that women of color see themselves reflected in the faces of their health care providers. Lynch and Pugh pose the question: "Are the values and priorities of non-European-American patients known and appreciated by European-American health care providers?" An even deeper or more provocative question the authors of "Uneven Ground" pose is: "Are white health care providers, pharmaceutical companies and government programs to be trusted?" (Lynch, 2000). Trust is an issue raised when addressing access to healthcare or the lack thereof. Certain *communities of color* have historically suffered from discrimination or have had negative experiences when seeking healthcare; therefore, trust is an issue. Receiving care from the same primary care provider (doctor or nurse) – may increase a patient's level of trust for this provider. Good patient-provider communication in turn, increases the likelihood that the patient receives appropriate care (Starfield, 1998). Hispanics of every income and educational level are less likely than respective non-Hispanic Whites to have a "usual" (the same) provider (National Health Disparities Report, 2005).

The implications of the lack of culturally competent providers can be viewed as a barrier and will result in deterring some Latinos from accessing care. Policy strategies to increase the cultural competence of staff at health settings and to increase the number of providers of color are needed. For example, health care systems should be encouraged to invest in hiring and training bilingual staff and Latina peer educators that can conduct outreach and HIV prevention and testing in the Latino communities (Rios, 2006). This would serve to improve access to HIV testing and counseling as well as increase the

success rate of Latinos adhering to their medications. Throughout the next decade, Healthy People 2020 will assess health disparities in the U.S. population by examining social determinants of health. The Healthy People 2020 initiative recognizes that other influences of health include such factors as having access to culturally sensitive health care providers (www.healthypeople.gov.)

Latinas who live near the *frontera* (border) experience a multitude of problems. Lack of access to care or poor health care is a major problem for Latinas and their children who have to rely on rural health care services. There are often no specialty medical services for Latinas who are HIV-infected. Since extreme poverty affects many Latina-headed households in rural areas, HIV is not always the most significant stressor. Women are most likely to devote their energies to addressing immediate needs of food and housing for their family over medical care for themselves, particularly if they are asymptomatic (HRSA, 1998).

Gender inequality in interventions is another form of oppression Mexican American women experience. For example, Latinas involved with a Latino male partner are often encouraged by HIV educators to practice condom negotiation. This can pose a potential risk for domestic violence if their partners suspect infidelity as a result. If a woman insists that her partner use a condom, the implication may be construed to mean that he, or even she, has been "unfaithful." For women who are already victims of domestic violence or who fear becoming such victims, negotiation of safer sex practices

is even more difficult, thus magnifying the risks of becoming infected with HIV (Horwitz, 1998).

Another type of oppression grounded in gender inequality is related to the social role Mexican American women play in their culture. For example, they are taught not to ask questions regarding their partner's indiscretions, which could ultimately put them at risk for acquiring HIV. Since married and single women are likely to face somewhat different situations in regard to the participation of their partners in behavioral risk reduction, educational and behavioral change strategies may need to be tailored accordingly (Amaro, 1988).

Upon release, incarcerated men who have had unprotected sex or used infected needles while in jail or prison can pose a serious risk to their female partners. HIV prevention efforts inside of the jails and prisons, including condom availability is inconsistent at best. Moreover, little is known about the risk of HIV transmission after release from prison, as former inmates transition back to their communities. To date, there have been no studies specifically focusing on behavioral risk for HIV among Latinos with histories of incarceration (Johnson & Raphael, 2005). The best and most recent available data in risk behavior with relevance to Latinos comes from a case control study of 305 incarcerated HIV-positive Black men which found that among men who reported engaging in anal sex, twice as many reported never using a condom during "homosexual sex" in prison compared to those who reported never using a condom with male partners outside an institutional setting (Lichtenstein, 2000). The fact that Latinos

are over-represented in the prison system suggests a potential risk to their female sexual partners. In 2000, 32.3% of the federal prison population was Latino (non-U.S. citizens accounted for 29.9% of the overall population). Moreover, in 1998, although Latinos represented 16% of all incarcerated males in federal and state prisons combined, they represented 32%, 27%, and 34% of male inmates in New York, Texas and California respectively that same year (NASTAD, 2002).

Another risk, common to Mexican American women, is being the partner of a Mexican migrant farm worker. This group suffers a high incidence of HIV. One contributing factor is that some migrant laborers leave their spouses in Mexico and immigrate to the United States and engage in sex with secondary partners and use prostitutes. Another factor is that, in an effort to stay healthy, Mexican farm workers and their families inject medicine and vitamins they have brought to the U. S. from their home country. Needle-sharing associated with this activity places them at risk for HIV and complicates the care of those already living with the disease (HRSA, 1999). Factors such as men living away from home for extended periods of time, disrupted family ties, increased number of both male and female sexual partners, including prostitutes, place both migrant men, and the women who are their wives or girlfriends at risk for HIV infection (Hulewicz, 1994).

One subject not generally discussed in Mexican American households is that of men having sex with other men. In some instances this involves married men who consider themselves heterosexual. Thus, still one more risk of transmission for Mexican

American women is that their sexual partners may be engaging in sex with men and keeping it a secret. Mexican American men in particular, may never disclose that they have bisexual or homosexual tendencies. Jean Gochros (1989), who interviewed thirty-three women who were married to men who were having affairs with other men, states: "What we don't know is how many infected wives, former wives, or other female partners of gay/bisexual men are waiting in the wings about to become sick. We only assume that there are many. We do not have a completely reliable estimate of the degree of risk from either a 'category' or a specific sexual behavior" (p. 200). One reason for the lack of discussion of men having sex with men is that in Latino culture homosexuality and bisexuality is not acceptable and therefore denied by many who have a different sexual preference that is taboo. It is not uncommon for Latino men to continue to live with their wives who are heterosexual for years and engage in same-sex activities. A case study written by a social worker at *Mujeres Unidas* profiles a couple who had been married for twenty-eight years and had four children. Not until the husband took ill and was hospitalized and diagnosed with an opportunistic infection common to people with AIDS, did his spouse discover his diagnosis and the risk he had posed to her during their marriage. He admitted to having unprotected/anonymous sex in the park with other men. (*Mujeres* Case Study, 1995).

In summary, Lee and Covington, public health specialists in the Food and Drug Administration's Office of AIDS and Special Health Issues, argue that there are a number of common factors, many economic ones, affecting many minority groups that contribute

to the increase in AIDS such as a lack of medical insurance, which results in a lack of access to health care; a higher incidence of diseases or maladies in general; fear of medical care, particularly among "illegal aliens" (better defined as undocumented); limited or no means of transportation to get to a health clinic; and too few doctors, particularly in rural areas (Greeley, 1995). These multiple issues that can exist in the lives of Latinas are of great significance both as stand alone issues and combined, all of which have been discussed in other sections of this dissertation. If a woman is facing the issue of trust regarding her immigration status, she will most likely not seek care. If she does not have insurance or the means to get to the clinic, she will most likely not keep her appointments even is she is in care. And others who live in rural areas have difficulty in finding an HIV specialist that will see them for their care. All are challenges that can be found in the lives of women in general. The issue of poverty alone makes it clear that this can create barriers and challenges to accessing care.

Gender Issues

To understand the needs and know how to effectively serve Mexican American women living with HIV, social workers must understand unique factors related to this population. Central to such understanding is the issue of how gender has played a role since the beginning of the AIDS epidemic. Generally speaking, Mexican American women impacted by HIV share some common factors related to women in general

regardless of ethnicity and race. Several known health-related issues uniquely affecting women living with HIV disease also affect Mexican America women.

The first issue is that women are generally sicker than men at diagnosis, which leads to earlier death rates for women compared to their male counterparts. Carole Campbell postulates that compared with HIV-infected men, HIV-infected women face unequal access to care and unequal quality of care, which affects not only women and their children but also the women who care for HIV-infected family members. She argues compellingly that social institutions such as health care and the media have created barriers for women because they fail to take into account the differences between men and women in social roles, status, and power (Campbell, 1999). Latinas continue to learn of their HIV status later in the disease process, missing the opportunity to receive early access to an array of life enhancing health and social support services. Latinas not only test for HIV later and enter care at later stages of HIV disease but exhibit higher viral loads and lower CD4 counts at entry than their male counterparts (DHHS, 2004).

A contributing factor to why women go undiagnosed or are diagnosed late in the disease process is women tend to exhibit different HIV-related symptoms. Another distinction is that the disease seems to take on different patterns of manifestation for women. For example, gynecologic infections are the most commonly reported condition of women living with HIV disease and AIDS (Project Inform, 1998). Although this is a commonly reported condition experienced by women living with HIV, physicians often

overlook or misdiagnose it because they do not suspect that the patient is "at risk" for HIV infection.

Another factor is that few clinical trials include women. Early in the epidemic, women were not enrolled in HIV-related clinical trials, resulting in limited knowledge of the action, safety, and efficacy of drug therapy for women with HIV-infection (HRSA, 1999). Thus, exclusion from research and clinical drug trials has negatively impacted women's health and perhaps hastened progression of the disease for individual women (Gallego, 1998). The historical trends that have shaped the inclusion of women have been ascertained by closely examining the historical timeline discussed earlier which reflects the little attention given to women in the early days of the epidemic (e.g., NIH rejected a proposal for a research study to determine whether women acquired AIDS in 1982). It took the efforts of ACT UP to organize a protest to "Storm the NIH" demanding more HIV treatments and the expansion of clinical trials to include more women and people of color in 1990 (HRSA, 2003). By speaking to Mexican American women living with HIV, the consequences of delayed care were explored, especially as it relates to the barriers that keep them from seeking care and how they cope and make meaning of this experience.

The second issue is that injection drug use is now the second most frequently reported risk behavior for HIV infection among women. About 61% of all reported cases of AIDS among women were associated with injection drug use or sex with a drug-injecting partner (HRSA, 1998). Although IV drug use is a known mode of transmission,

few drug treatment programs are sensitive to women's needs, especially when children are involved. Early in the AIDS crisis, CDC describe women as "vessels of infection and vectors of perinatal transmission;" thus, they were viewed not as individuals needing medical attention, but as sources of infection to others, i.e., to men and children (Faithfull, 1997). There is a great deal of blame and stigma related to perinatal transmission due to societal pressures and prejudices related to women with drug problems.

Poverty is a third issue to consider when examining differences between men and women whose lives are impacted by HIV/AIDS. HIV/AIDS among women in the United States is, to a large degree, related to an epidemic of poverty and its associated problems. Most women with HIV were poor before becoming infected and will become poorer as their disease progresses. Throughout this dissertation, "poor" is defined as having met the U.S. guidelines of the 2007 Federal Poverty Level (Federal Register, 2007). Recent studies in developed countries have shown AIDS incidence to be highest among the very poor, although the international definition is not the same as the U.S. definition. If these trends are replicated worldwide, AIDS will become like other infectious diseases. It is already a disease of poverty in the sense that it affects more poor people than non-poor (World Bank Organization, 2000).

Finally, many women are also faced with the dual challenge of being both patient and caregiver of a child/ren, a spouse or a partner. As women living with AIDS struggle to continue care-giving responsibilities, they must also wrestle with the grief and loss

issues that accompany their own terminal illness (Hackl, Somlai, Kelly and Kalichman, 1997). The issue of permanency planning for their children inevitably arises because the majority of women with HIV/AIDS involve women are of child-bearing age and this has a great impact on women and their families. Custody planning forces a woman to address complex and emotionally charged issues. Some women find it impossible to go through the planning process. It is not unusual for a woman to wait until end-stage disease or forego making guardianship arrangements (Taylor-Brown, 1998).

Theoretical Concepts

The discussion of such issues as poverty, gender-differences, oppression and other forms of discrimination on Mexican American women living with HIV has outlined some of the barriers that exist for this population. Just as important, the strengths individuals and groups bring to adverse conditions such as this should be discussed. Theories that examine health-promoting behaviors across the life course and focus on environments that promote personal, family, and community are valuable to social work practice. These theories can support social workers recognize a client's ability to persist in the face of obstacles and to proceed positively with life events—or what Saleebey (1996) has called "a practice based on the ideas of resilience, rebound, possibility, and transformation" (Greene, 2002).

Theories of Strengths and Resiliency

The theories to be presented in this study of how Mexican American women living with HIV cope and make meaning of their illness are adapted from the Strengths Perspective/Resiliency model. Researchers have long concluded that just as people face risk factors, they also experience protective factors that help them cope and prevent future problems. Grothberg (1995) defines risk factors as conditions that increase the likelihood that a child or other individual will develop a problem and protective factors to be conditions that buffer, interrupt, or prevent problems from occurring (Greene, 2002). Though the research shows that studies of "children at risk" marked the beginning of the exploration of the theory of resilience, studies have examined adult survivors of traumatic and adverse life experiences, which have helped shape current theories of resilience. For example, Moskovitz (1983) and Lifton (1968) have studied adult survivors of Nazi Holocaust and both identified that their subjects displayed resilient behavior patterns. Theorists have continued to urge social work educators to base human behavior content on a resilience approach to increase the emphasis on client strengths and resources. Saleebey (1997), a leader in the strengths-based practice movement, has propounded the idea that students receive human behavior content for understanding resilience-based practice because the resilience literature satisfies many tests of a strengths-based HBSE (human behavior and the social environment) curriculum: it provides ways of thinking about individual and collective assets; it situates the focus of concern in the larger social

context; and it traverses the range of experience and response from biological to psychological to social (p.21) (Greene, 2002).

The concepts of strengths and resilience overlap. Strengths refer to those sets of attributes that people posses in life that help them cope with life issues. Resilience refers to the ability to cope with serious traumas and stressors and not to be significantly affected by them. Henry (1999) suggests that the notion of resilience was created to help explain why some children do well under very troubled circumstances (Baldwin et al. 1993). Resilience describes children who grow up in highly unfavorable conditions without showing negative consequences (Masten 1984; Okun et al. 1994; Radke-Yarrow & Brown 1993; Werner, 1992). Henry (1999) defines resilience as "the capacity for successful adaptation, positive functioning, or competence despite high risk, chronic stress, or prolonged or severe trauma" (p. 521). Abrams (2002), in a further definition of resilience, indicates that resilience may be seen as the ability to readily recover from illness, depression, and adversity. Walsh (1998) defines resilience in families as the "capacity to rebound from adversity, strengthened and more resourceful" (Glicken, 2006).

One such population of adults that may be challenged to find active coping strategies are Mexican American women living with HIV. This study will explore whether and how resilience affects coping abilities and the way in which they make meaning of their HIV diagnosis. One assumption that can be drawn is that Mexican American women living with HIV can potentially find themselves alone and isolated

without the support needed to cope with such things as who to tell about their seropositive diagnosis, when to disclose to their children, how to begin permanency planning for their children, the decision to continue or terminate a pregnancy, the lack of medical professionals who are knowledgeable about the medical and gynecological conditions common among women with HIV, etc. These are but a few possible stress-inducing situations that may be considered gender-specific among women living with HIV. These burdens are made worse by the absence of supportive family relationships to assist women in effectively coping with these stresses, often not being prescribed the latest therapies, and barriers that poor women and women of color experience in accessing health care (Pequegnat, W. & Szapocznik, J, 2000). Each of these issues has been addressed in previous sections of this discussion as contributing factors that affect the lives of Mexican American women living with HIV.

Further complicating these stressors are the pressures and fears which may be provoked if the woman is undocumented and the distrust of any system that could possibly lead to deportation. An even bigger challenge is receiving care in their native country of Mexico, Honduras, or other places in South and Central America whereby services for people with HIV may be extremely limited, not to mention that stigma is oftentimes greater in these communities. Once deported, the challenge and struggle of coming back into the United States makes is next to impossible due to certain laws that do not permit people that are HIV to enter the United States. In fact, while serving as United States president, Bill Clinton signed the U.S. HIV Immigration Ban into law in

1993 (http://www.actupny.org/actions/immigration.html), an act that many AIDS activists consider a betrayal of the Clinton Administration.

Theories of Coping

Many definitions of coping have been introduced in social work. Nevertheless, there seems to be a growing agreement among professionals (e.g., Lazurus, Averill, and Opton, 1974; Lazurus and Folkman 1984a, 1984b; Murphy 1962, 1974; White 1974) that coping refers to an individual's efforts to overcome demands (conditions of harm, threat, or challenge) that are appraised (or perceived) as exceeding or taxing his or her resources (Monat & Lazarus, 1991). Folkman and Lazurus (1980) have suggested a taxonomy of coping which emphasizes two major categories, problem-focused and emotion-focused modes. Problem-focused coping refers to efforts to improve the troubled person-environment relationship to changing things, for example, by seeking information about what to do, by holding back from impulsive and premature actions, and by confronting the person or persons responsible for one's difficulty. Emotional-focused (or palliative) coping refers to thoughts or actions whose goal is to relieve the emotional impact of stress (i.e. bodily or psychological disturbances). These are apt to be mainly palliative in the sense that such strategies of coping do not actually alter the threatening or damaging conditions but make the person feel better. Traditionally, emotion-focused modes of coping (particularly defense mechanisms such as denial) have been viewed as pathological or maladaptive. On the other hand, denial can initially serve a positive

function (cf. Hamburg and Adams, 1967, Lazarus, 1983, Visotsky et al, 1961) in preventing a person from being overwhelmed by a threatening situation where the possibilities for direct actions are limited and/or of little use. In general, then, emotion-focused modes of coping may be damaging when they prevent essential direct actions but may also be extremely useful in helping a person maintain a sense of well-being, integration, or hope under conditions otherwise likely to encourage psychological disintegration (Monat & Lazarus, 1991).

The concept of coping is not a new one and was introduced over fifty years ago. It is found in two very different theoretical/research literatures, one derived from the tradition of animal experimentation, the other from psychoanalytic ego psychology. This approach is heavily influenced by Darwinian thought, according to which survival hinges on the animal discovering what is predictable and controllable in the environment in order to avoid, escape, or overcome noxious agents. The animal is dependent on its nervous system to make the necessary survival-related discrimination. In the psychoanalytic ego psychology model, coping is defined as realistic and flexible thoughts and acts that solve problems and thereby reduce stress. The main difference between the treatment of coping in this model compared to the animal model is the focus on ways of perceiving and thinking about the person's relationship with the environment. Another difference between the models is that the psychoanalytic ego psychology approach differentiates among a number of processes that people use to handle person-environment relationships (Monat & Lazarus, 1991).

Cervantes and Castro (1985) discuss the importance of cultural specificity in the stress-mediation-coping process as it may appear under certain conditions in certain subgroups of Mexican Americans. They pose the following questions: Are there certain situations or domains in which culturally specific coping patterns will manifest themselves for most Mexican Americans? Alternately, are there certain homogeneous subgroups within the general Mexican American population who experience group specific stress-coping patterns which increase the risk of developing a certain mental disorder such as alcohol abuse, eating disorders, or dysthymic disorder? They go on to say little is known about how various homogeneous subgroups of Mexican Americans, for example, low-acculturation elderly females, each differ in their subjective cultural beliefs toward stress and illness, in their coping styles, in available coping resources, and how these variables contribute to certain short- and long-term mental health outcomes. How can population-wide mental health intervention programs or individualized therapies which purport to improve mental health be developed and delivered in the absence of sufficient systematic knowledge of specific risk factors for mental disorders? (Cervantes & Castro, 1985). Although this is somewhat dated information, it is still applicable today in determining the coping skills of Mexican American women living with HIV. It is important to examine individuals' level of assimilation and acculturation while determining the most effective coping mechanisms for this population.

In exploring the experiences of Mexican American women, it will help to look at both their risk and resiliency factors as well as the strengths that they bring to this experience and determine if these contribute to their coping skills.

By utilizing a model of partnering the strengths perspective and resiliency in this dissertation it will be possible to gain insight as to whether or not resiliency plays a role in the lives of Mexican American women living with HIV while simultaneously searching for the strengths found in this population. Additionally it will allow for the exploration of these strengths and help identify them as those possessed or acquired through empowerment leading them to coping well with their illness

In summary, this chapter presented a historical view on HIV and brought it to the current trends and detailed the way HIV has impacted the lives of women and more specifically, Mexican American women. The chapter's discussion on important factors related to how these women cope and make meaning of their HIV status and the way they seek help was intended to raise awareness to the cultural factors and needs of Mexican American women. Salient points were made in regards to health disparities, poor access to healthcare and the barriers that exist in contributing to this issue and how race, gender and class play a role in this unequal playing ground. Lastly, theories were introduced in relation to strengths and resilience as well as coping to better understand how Mexican American women living with HIV find the power to overcome the barriers they face and live with pride and dignity.

Chapter Three

Conceptual Framework for the Present Study

The conceptual framework for the present study of how Mexican American women living with HIV cope and make meaning of their illness is adapted from the Strengths Perspective and the Resiliency model. It is necessary to demonstrate how the two models are blended and how they relate to this dissertation.

Strengths Perspective and Resiliency Model

A growing literature argues the value of the Strengths Perspective/Resiliency enhancement paradigm in clinical practice. Many authors applaud this approach as a means of counterbalancing the traditional clinical emphasis on illness and dysfunction (Chazin, Kaplan, & Terio, 2000). While certainly not a new concept in social work, the literature explicitly presents and further develops basic theoretical concepts underlying this approach (Cowger, 1994). The literature applies this model to clinical work with diverse client populations such as homeless children (Felsman, 1984; Douglaus, 1996); adolescents and young adults (Rosenbluth, 1986); homeless women with children (Thrasher & Mowbray, 1995); and older adults (Perkins & Tice, 1995; (Norman, 2000).

The strengths perspective is useful in the current study because it allows the strengths of Mexican American women living with HIV to surface while exploring the primary research question of how they cope and make meaning of their HIV diagnosis.

Furthermore, since this model has been used clinically with diverse populations it promotes its utility with a sub-population of individuals of a specific ethnicity living with HIV and allows for cultural factors to be identified and explored as positive attributes in viewing a person's individual strengths.

Strengths Perspective

A leading expert in the field of Strengths Perspective, Saleebey (1996) notes, clinical practice continues to focus on pathology and dysfunction (Norman, 2000). In his edited book *The Strengths Perspective in Social Work Practice*, Saleebey (1997) states that at present, the strengths perspective is just that – a perspective, " a way of thinking," an approach to practice.

The strengths perspective is one that takes social workers away from the traditional disease model, which highlights pathology. Momentum has developed to concentrate professional practice on coping rather than on risk, on opportunity rather than fatalism, on wellness and self-repair rather than on illness and disability. It is defined as a change from a medical damage model which focuses on curing illness to a health model that concentrates on promoting health (Norman, 2000; Rutter, 1989; Weick, 1986; Wolin & Wolin, 1993). In social work this model and emphasis has been referred to as "the strengths perspective" (Saleebey, 1996). Rather than teaching people evermore sophisticated formulations of their problems, social workers can help people learn to recognize and appreciate their strengths, thereby enabling them to take control of their

own lives and solve their own problems (Weick et al., 1989). Furthermore, the strengths perspective (Saleebey, 1997) is based on the fundamental idea that everyone has strengths that constitute the primary instruments of change. The push to change the field's (social work) predominant paradigm from pathology to strength began in the early 1980s. Weick (1983) strongly advocated the "growth-task model" of human development, emphasizing the idea that all people have an inherent push for growth and that a focus on the tasks of growth fit well with social work's interest in client empowerment. Continuing this theme Weick (1986) suggests a "health model of social work." Believing that healing-either biological, psychological, or social – is an inherent capacity of the human organism (Norman, 2000).

Following the suggestions of Saleebey to look at clients "in the light of their capacities, talents, competencies, possibilities, visions, values and hopes," helps to identify the common themes in this study. It helps to explore how Mexican American women living with HIV cope and make meaning of their diagnosis rather than focusing on the risk this possesses to their well being. It helps to address the following sub-questions: (1) What are your strengths that help you cope and make meaning of your HIV diagnosis and help you live your life in a positive way? (2) What are your talents and competencies that help you survive adverse conditions? (3) How have you adapted to living your life with HIV?

Resiliency Theory

Resiliency is the ability to bounce back from, or to successfully adapt to, adverse conditions. Resiliency is defined as "successful adaptation under adverse conditions" (Luthar & Zigler, 1991:8), or as the factors and processes enabling sustained competent function even in the presence of major life stressors (Masten, Best, & Garmezy, 1990). Resiliency combines the interaction of two conditions: *risk factors* – stressful life events or adverse environment conditions that increase the *vulnerability* of individuals – and the presence of personal, familial, and community *protective factors* that buffer, moderate, and protect against those vulnerabilities. Individuals differ in their exposure to adversity (vulnerability) and the degree of protection afforded by their own capacities and by their environment (protective factors). A person's ability to recover, to adapt, or to bounce back to a normal condition (*resiliency)* varies over the person's lifetime, as well (Norman, 2000).

Howard Goldstein (1997) defines resiliency as the attribute, the concept, the process, that epitomizes and operationalizes the strengths perspective. Although social workers have long sought a framework that focuses on client strengths, the profession has yet to adopt a multi-systemic, empirically based theory that can be applied in assessment and intervention across people's life course. Resiliency theory is such an emerging paradigm (Greene, 2002).

Fundamental beliefs provide a foundation for work, but do not provide an actual blueprint for practice. While the strengths perspective provides a context for thinking

about the nature of the helping process, it does not suggest specific areas in which to intervene. By incorporating knowledge about risk and resiliency factors, a framework within which to build upon specific strengths of individual clients and their environments is constructed (Phillips & Cohen, 2000).

In exploring the experiences of Mexican American women, this study examines both their risk and resiliency factors as well as the strengths that they bring to this experience and determine that these in fact, contribute to their coping skills and practices. Some sub-questions asked in this study using this model included: (1) What role does family play in determining potential strengths of Mexican American women living with HIV? (2) What are some of the pathways (from a strengths perspective) that have led Mexican American women to seek mental health services outside their family? (3) What motivates Mexican American women living with HIV to want to change stress inducing situations and lead healthier lives?

Combining the strengths perspective and resiliency model in this study, provided insight about the role resiliency plays (as a strength) in the lives of Mexican American women living with HIV. Additionally it allowed for the exploration of this concept and other strengths which may have led these women to a level of empowerment and allowed them to seek help.

The conceptual framework described above presents a view of how the Strengths Perspective and Resiliency model combined are relevant to this dissertation and its population. These interrelated models aided in the exploration of the primary research

questions in this study that helped to answer the overriding research question of how Mexican American women living with HIV cope and make meaning of their diagnosis.

The next chapter will explain the methods used to explore the research questions and how these models may further explain the research findings.

Chapter Four

Methodology

The research question guiding this dissertation is: *How do Mexican American women living with HIV cope and make meaning of their diagnosis in the context of their past and current life experiences?* In particular, this researcher examined references made to their HIV diagnosis in relation to their family and other personal relationships and how this diagnosis is experienced within the context of other life challenges and/or life stressors.

Rationale for Selection of Methods

Qualitative methods are well-suited to research concerned with sensitivity and emotional topic[s] or seeking to capture the 'lived experience' from the perspectives of those who live it and create meaning from it (Padgett, 1998). The topic of HIV is a highly sensitive and personal phenomenon and one that has not been extensively studied from the perspective of Mexican American women living in South Texas. The sensitive nature of an HIV diagnosis alone calls for a more open-ended qualitative methodology. Ethnography, in particular, is sensitive to personal meanings and cultural context and each is integral to this investigation.

Therefore, this dissertation used a qualitative research methodology, specifically, an ethnography. Ethnography is a description and interpretation of a cultural or social group or system from the point of view of the people who inhabit that culture (Creswell, 1998; Rubin & Babbie, 1997). The final product of this effort is a holistic cultural

portrait of the social group that incorporates both the views of the actors and the researcher's interpretation of views about human social life using a social science perspective (Creswell, 1998). Ethnography has its genesis in cultural anthropology through early 20th century anthropologists such as Boas, Malinowski, Radcliffe-Brown, and Mead and their studies of comparative cultures (Atkinson & Hammersley, 1994).

This ethnography involved fifteen (15) women who are currently involved with or who have previously been involved with *Mujeres Unidas Contra el SIDA (Mujeres)*. The sample was kept to this size because the participants participated in more than one in-depth interview, and were observed in their participation in other activities held at *Mujeres.* Participation Observation was utilized since the researcher worked at *Mujeres* and was able to have regular contact with the study participants. The study participants were observed as they attended support group sessions, engaged in public speaking as peer educators, and attended staff meetings and planning meetings for events, etc. Additionally, this sample size sufficed in using a type of quota sampling. This researcher interviewed current and past members of the support group of *Mujeres Unidas*, leaders and non-leaders, newly diagnosed women as well as women who have been living with HIV for an extensive period of time, i.e. more than ten years. The intent was to keep the general principles of representativeness in mind while conducting the interviews. As Rubin and Babbie (1997) state, if the group or social process under study has fairly clearly defined categories of participants, some kind of quota sampling might be used: persons representing all different participation categories should be studied (p. 383).

The researcher explored questions relevant to how participants of this study are living with HIV. Specifically, the study documented the experiences of Mexican American women and brought voice to the coping strategies they adopted in living with HIV and make meaning of their diagnosis. It further explored the issues of gender, race, and culture and how they operate to influence, shape, and construct their lives through intensive and extensive interviews with Mexican American women living with HIV in San Antonio. The study focused on women who attend or have attended at least one support group session at *Mujeres.* In some cases this may be one of the few social networks they have, and they may otherwise live in isolation due to the social stigma that is associated with HIV. This group provides these women with a safe forum in which to recount their stories.

Qualitative research questions, in contrast to quantitative research questions, are intended to be open-ended and revised throughout the process of the research (Creswell, 1998; Padgett, 1998). Because all questions contain assumptions, qualitative researchers take special care in identifying and acknowledging the assumption embedded within the research question (Creswell, 1998). The research question guiding this study is: *How do Mexican American women living with HIV cope and make meaning of their diagnosis?* The purpose of this study is (1) to explore cultural and psychosocial factors influencing the meaning of HIV disease among Mexican American women; (2) to identify coping strategies and examine the impact of social support on the lives of these women; and (3) to examine both resiliency factors as well as the strengths the women bring to their

experience with HIV to determine if these contribute to their coping skills and practices and promotes positive functioning.

Research Design

Selection of Participants

Qualitative research designs generally do not use random sampling techniques, allowing the researcher to focus on a particular marginalized group, such as Mexican American women living with HIV. Since groups such as these are typically hard to reach due to mistrust of "outsiders," researchers may have difficulty identifying individuals to participate (Padgett, 1998; Rubin & Babbie, 1997). Therefore, this study utilized a purposive sample with the goal of identifying women who fit the criteria of being Mexican American, between 18-60 years old, having been diagnosed with HIV within the last month to 20 years, and having attended at least one session of a *Mujeres Unidas* support group.

Since individuals from marginalized groups have historically experienced mistreatment, predisposing them to be suspicious or mistrustful of authority figures, including researchers, additional time and care may be required to build trust and rapport with respondents (Mc Roy, 2002). Due to the paucity of qualitative research specifically focusing on Mexican American women living with HIV, the fact that study participants know the researcher minimizes the issue of mistrust. In fact, the women expressed how

comfortable they were in speaking to this researcher resulting in more openness and adding to the richness of their stories.

The ethnographer made the assumption that the participants were the experts about their lives and relationships and assumed a position of naiveté to avoid making erroneous assumptions about the participants' experience and personal meanings (Creswell, 1998; Spradley, 1979). This point is important because it allowed the participant to tell her story in her own words in response to open-ended questions. Broad open-ended questions allowed each respondent to emphasize what she thought was important and worth sharing. Lofland and Lofland (1995) suggest that investigators adopt this role when interviewing. The investigator should offer herself as someone who does not understand the situation she finds herself in and must be helped to grasp even the most basic and obvious aspects of that situation (Rubin & Babbie, 1997)

Sample Selection and Site Used

The sample for this study consisted of Mexican American women with HIV residing in San Antonio, Texas. This area was selected due to the high concentration of Mexican Americans in San Antonio and the fact that there is a specific agency that provides support group services specifically designed for Mexican American women living with HIV/AIDS through a community-based organization known as *Mujeres Unidas Contra el SIDA (Mujeres)*. The researcher had worked in the field of HIV for

over twenty years when the interviews took place and was familiar with the population and had ready access to the participants in the study.

San Antonio was an optimal site for this type of research study for several reasons. San Antonio is the 9th largest city in the U.S. and is expected to grow at an annual rate of 1.9% through the year 2010. Although, HIV is not exclusively found in urban areas, it is more likely that there will be more identified cases in urban areas versus rural communities due to access to care issues. This assisted in identifying potential study participants. San Antonio is approximately 55% Latino, 38% Anglo, and 7% African-American. Since infection rate among Latinas as a proportion of all Latino AIDS cases, continues to climb since the beginning of the epidemic, it poses concern regarding HIV cases in San Antonio and how this increase potentially impacts Mexican American women. For example, the infection rate climbed from 15% in 1990 to 23% in 2002, which represents a 53% increase in the number of Latinas with AIDS since 1990 (Rios, 2006). By focusing on a sub-population of Latinas in South Texas, this study will be a contribution to examining the answers to important research questions that can be used as guides in other parts of the country. For the purpose of this study, South Texas is defined as the southern tip of Texas, which may be separated from the rest of the state roughly by a line drawn from Del Rio eastward to Austin and from Austin southeastward to Corpus Christi (Texas State Historical Association, 2010).

The median household income for residents of San Antonio is $43,100, which is under the U.S. median income of $50,200 (U.S. Department of HUD, 2005). The

majority of women living with HIV fall under the poverty guidelines and are living on a fixed income involving SSI or SSDI. Poverty plays a particularly negative role in the lives of Latinas, and given their traditional responsibility as heads of household, the consequent increase for HIV/AIDS risk is also felt by the entire family. Research shows that the annual median wage for Latinos is almost half of their non-Hispanic White counterparts (Aguayo, Brown, Rodriguez, & Margolis, 2003). Close to 25 % of Latino households are headed by single Latinas who are the lowest paid wage earners of any group (U.S. Department of Labor, 2004). Women from economically disadvantaged backgrounds have to deal with many social and psychological adversities that make it difficult for them to practice healthy behaviors, including their ability to access available services (Castañeda, 2000).

Bexar County constitutes the third highest number of HIV/AIDS cases in the state of Texas according to the Texas Department of Health-Annual Report of 2003 (TDH, 2003). At the time of data collection, Bexar County had experienced a large increase in new cases of HIV among women. The FFACTS Immunosuppression Clinic with the University Health System, which sees the majority of indigent patients with HIV/AIDS, reported to have slightly over 400 female patients with well over half of them being Latina (Personal Interview with Tracy Talley, 2006). This fact validates the need for more research to be conducted among Mexican American women living with HIV in San Antonio and to illustrate how important it is to understand how they cope make meaning of their HIV diagnosis.

Recent immigrants and monolingual Spanish-speaking persons are not a high priority and few agencies are attempting to reach them. Undocumented Latinos are ineligible for almost all publicly-supported health benefits except for limited emergency services. In addition, undocumented Latinos often experience additional barriers to HIV testing due to the recent increase in deportation raids, which have resulted in substantial decreases in clinic and hospital visits and appointments, many for preventive care such as prenatal visits (NCLR, 2004b). Even when documented, immigrant Latinos are the least likely to have health insurance and often cannot afford the time missed from work to attempt to access care (Morales et al., 2004). At the time of data collection, it was well known that *Mujeres* provided services to women in need and did not inquire about legal status.

The only gender-specific grassroots organization in South Texas and Central Texas specifically targeting HIV positive Latinas and their families is *Mujeres.* It was founded in 1994 as a direct response to the large gap in services in San Antonio for bilingual/bicultural Latinas and their families whose lives are directly impacted by HIV/AIDS. Services include support groups, individual counseling, community outreach and education, information and referral services, advocacy training for peer educators, all of which utilize a *familia* (family) approach. This non-profit organization is supported through private foundation monies, sub-contracts with other AIDS Service Organizations (ASOs), and fundraising efforts.

To date, *Mujeres* has served over 300 Latinas who have been directly impacted by HIV/AIDS, the majority of the members (past and present) have been women infected and affected by HIV/AIDS. Currently fifteen Latinas are core members of the organization; they also serve as volunteers and another ten Latinas are from the community-at-large are agency volunteers.

Over the years, *Mujeres* has increased its visibility both locally and nationally. Recently, it was featured in a nationally televised program on *Univision* discussing how AIDS has impacted Latinas/Latinos 25 years after it was identified. On December 13, 2006, *Mujeres* was one of five (5) Latino-serving organizations in the United States invited by the National Latino Commission on AIDS to meet with Dr. James Fenton, Director of the National Center for HIV, STD and TB Prevention from the Centers for Disease Control and Prevention (CDC) and his staff to discuss their response to the increase in HIV infections in Latino communities across the United States and Puerto Rico**.** A primary concern raised at this meeting was the alarming data on HIV infection among Latinos and that they represent one of every five HIV infections. Furthermore, this proportion continues to rise, particularly among Latinas (CDC, 2006). As is evident, *Mujeres* is a reputable organization that is best known for its service to Latinas with HIV and, therefore, a good site to recruit potential participants for this study.

This researcher worked in the field of HIV/AIDS for twenty-two years and was affiliated with *Mujeres* as its Founder and Volunteer Executive Director since its inception in 1994 until August, 2009. During her tenure in the HIV field, she established

a good rapport and trusting relationship with the population served, which assisted in the recruitment of participants for this research study. This researcher facilitated all support groups offered at *Mujeres* until August, 2009. Due to this involvement she earned the trust of the members/clients interviewed for this study.

Therefore, this researcher's past and present work experience in the HIV/AIDS community and living in this area broadened her understanding of the issues faced by women living with HIV and has created a ready-made trust which is often difficult to establish while conducting a qualitative study. While bias may exist when a researcher is so close to the population studies, the trust and acceptance were critical to exploring the participants' lived experience. To ensure that participants did not feel pressured to participate in this study due to their relationship with the researcher, professional colleagues administered the consent form, explained the purpose of the study, explained the selection criteria, explained the interview process, and finally, emphasized that participation was voluntary and that the decision not to participate, this decision would in no way affect their relationship with *Mujeres.*

It is clear that the potential for bias does in fact exist, as with any research, and it should be noted that special effort was made to prevent any bias from occurring due to the researcher's connection with *Mujeres*. Because of her role at the organization where participants were recruited is one of long-time professional acquaintance, the women involved in this study may not have wanted to say anything negative about their experiences with the organization during their interviews and may have wanted to show

support of the researcher. However, due to the researcher's relationship with some of the participants this actually had a positive impact by providing the entry into collecting data as they felt more comfortable in speaking to her about their concerns. In summary, the benefits out-weighed the biases, especially in light of the proactive measures taken to make the participants feel free to be as honest as they could be to help with the findings. Historically, members of this same group of women (many of whom participated in this study) have taken their role in participating in other research projects seriously and their main goal is to bring the issues that they face and live with every day to light.

The researcher met with the Director of Administration of *Mujeres* and reviewed the research study in detail. She explained the study's goals of the study and the criteria for selecting study participants Information Sheet (Appendix A) as well as the Recruitment Flier (Appendix B) and asked that she post the flier in a place where it was easily visible. The researcher asked that she make verbal announcements at meetings to accommodate the needs of those who had literacy problems. She was also asked if she was willing to be a back-up contact for women to call and schedule their appointment for an interview. Lastly, the researcher emphasized to the Director of Administration the importance of explaining confidentiality to potential study participants in order to prevent any potential harm experienced by the women while participating in this research study.

Data Collection Instruments and Procedures

Data was collected using of ethnographically informed interviews with mostly open-ended questions. The Demographic Questionnaire (Appendix E) consisted of semi-

structured questions that helped to gather important information about each participant. Another set of questions was used as probes (Appendix F) when needed in the interview. This approach facilitated the process by allowing participants to express themselves (using their voice) in describing their experiences in coping with HIV and make meaning of their diagnosis.

Interviews were scheduled at a convenient time for the participant where she felt safe and comfortable whether it took place at *Mujeres* or in their own home or another designated location that ensured privacy, especially due to the confidential nature of the participants' HIV diagnosis. The interviews lasted from one to two hours in duration. If the interview was not completed in this time frame, a second interview was scheduled. Second interviews were conducted only when needed to gain greater depth and insight, or when pursing emerging themes from other interviews. The tape-recorded interviews were conducted in both English and/or Spanish, depending on the participant's preference. Tape-recorded interviews were transcribed verbatim by the researcher or by someone contracted by the researcher. If a contractor transcribed an interview, the researcher went back to check for accuracy against the audio-taped interview. After each interview, the researcher removed all identifying information from the audio-tapes, the transcripts and any other written notes. All data collected was kept in a locked cabinet at the researcher's home office. All tapes will be destroyed at the conclusion of the research project.

Through these interviews, the researcher elicited Mexican American women's accounts (in their own words) of their daily lives and their personal experiences with their HIV status. By asking open-ended questions, participants shared their own unique experiences related to disclosing their status and how their lives have changed since their HIV diagnosis, a more in-depth look at their daily lives and personal relationships, especially as it relates to their own coping strategies and lastly to share their strengths brought to their lived experience with HIV.

Trustworthiness

It is important to establish trustworthiness of the data. Brody (1992) describes five methods for seeking trustworthiness in qualitative research: (1) triangulation, (2) thick description, (3) reflexivity, (4) member checking, and (5) searching for disconfirmation. The researcher used triangulation, reflexivity, and member checking.

Triangulation refers to the use of more than one research method to collect the same information. Having triangulated measures, the researcher is in a far better position to judge the credibility of her data than if she only used one measure (Rubin & Babbie, 1997). The researcher conducted in-depth ethnographic interviews to document the experiences of Mexican American women living with HIV, participant observation, utilized peer review sessions and member checks to corroborate all evidence in regards to her findings. Using more than one method of measurement to collect the same

information places the researcher in a better position to reduce the potential for measurement error.

Reflexivity involves reflections on the investigator's frame of mind and challenges her assumptions, values and feelings experienced as a result of the data collection and analysis experience (Brody, 1992). Having worked in the field of HIV/AIDS population being studied in this dissertation, this researcher was keenly aware that she was going into this study with some assumptions and biases. On the other hand, she also knew that her previous experience in serving these women, allowed her to gain the trust in them to speak with more ease and allow their voices to be heard adding to the richness of their stories.

The researcher utilized the technique of "member checks" by which she solicited the participants' views of the credibility of the study's findings and interpretations from the interviews conducted with them. Lincoln and Guba (1985) consider this the most critical technique for establishing accuracy and credibility (Creswall, 1998). The researcher utilized a peer reviewer who provided feedback as she wrote her findings, Dr. Olivia Lopez, who completed her doctoral studies at the University of Texas, at Austin having written a qualitative dissertation. The researcher maintained regular contact with the peer reviewer throughout the completion of this research study and kept all emails and notes from their discussions that were later used as a tool when writing her findings.

Data Analysis

The following is a list of the order of events that occurred while collecting data for this study:

- Audio-taped, in-depth interviews in English or Spanish took place at a site over a one to two hour period determined by the participant.
- If needed, a second interview was scheduled at a convenient time for the participant.
- Participant Observation took place at meetings, training sessions, and other activities that the participant and researcher were involved in at *Mujeres*.
- The interviews were transcribed verbatim by the researcher and/or a contracted transcriber.
- If the interview was conducted in Spanish only, this researcher used the original language and only translated the sections that were used as direct quotes in the dissertation.
- The researcher used field notes as a back up to ensure accuracy and listened to all taped-interviews and compared it to the transcription completed.
- The peer reviewer, Olivia Lopez, Ph.D., reviewed the research and discussed the findings on an ongoing basis.

- The researcher used member checking to verify credibility of the researcher's findings by having the study participants review her findings to determine if her interpretations were accurate.
- The researcher developed a thematic coding system to structure groups of themes as they emerged.
- The researcher will provide a copy of the dissertation to each of the study participants as agreed upon at the time of the interview.

Chapter Five

Results

This chapter presents the results of a qualitative study of fifteen Mexican and/or Mexican American women living with HIV who reside in the San Antonio area and who attended support group sessions at *Mujeres Unidas Contra el SIDA* since their diagnosis. All participated in one to two hour, in-depth, ethnographic interviews.

The first section of this chapter describes basic demographics of the participants along with family composition, socioeconomic factors, number of years living with HIV, and lastly, number of years involved with *Mujeres Unidas Contra el SIDA (Mujeres).*

The remaining section of this chapter is a synopsis of the study's principle findings according to the research questions presented on how Mexican American women living with HIV cope and make meaning of their diagnosis and it provides the common themes that emerged and their relationship to each other. It divides the themes into two main categories: *Strengths/Resources* and *Barriers/Stressors*. Finally, the chapter concludes with a discussion of the *Unexpected Findings* that surfaced in this study.

Demographic Characteristics

Table 1

Basic Demographic Characteristics

Variable	Number of Participants
Age (Median age = 41 years)	
18-24	**-**
25-29	**-**
30-39	**5**
40-49	**7**
50-59	**2**
60-69	**-**
70 +	**1**
Country of Origin	
United States	**11**
Mexico	**4**
Language Spoken at Home	
English	**5**
Spanish	**6**
English and Spanish	**4**
Highest Grade Completed	
No formal education	**-**
1^{st} – 6^{th}	**-**
7^{th} – 9^{th}	**2**

Table 1 (continued)

10^{th} -11^{th}	**2**
Completed High School	**11**
Completed GED	**1**
Technical School	**3**
Some College	**3**
College Degree	**3**

The age of the participants ranged from 33 to 70, with a median age of 41. The majority, ten of the women interviewed considered themselves to be Mexican-American, having been born in the U. S. Four were Mexican-born and lived in the U.S. and one was Puerto Rican. Of the fifteen participants interviewed, five reported to speak Spanish at home, five reported to speak English, and five reported to speaking both languages at home.

In examining data from the Texas State Data Center (TSDC), the report found that of the number of Hispanics (139,962-31%) in the San Antonio population for 2005 between the ages of 35-44, (43,438-31%) were uninsured compared to (16,077-15.1%) of Anglos and to (7,568- 30.1%) of Blacks. Of Hispanics (185,064) in the San Antonio population for 2005 between the ages of 45-64, (54,151-29.3%) were uninsured compared to Anglos (23,094-11%) and to Blacks (9,093-25.6%) (TSDC, 2005). The participants in this study are similar in that most were uninsured and the majority of them are in the age category of the highest percentage (31%).

In regards to educational level, the majority of participants, eleven graduated from high school, while two completed the tenth grade and two completed the seventh grade. Of the two women that completed the tenth grade, one went on to receive her GED. Of the fifteen participants, five reported to have had some college, three have attended a technical college for specific training and three have gone on to receive degrees to include a woman who received her Associates of Arts degree in Nursing, another woman who received a four year degree in Nursing (in Mexico), and one woman who received both a Bachelor of Arts degree and a Master of Science degree.

Family Composition

Table 2

Family Composition

Variable	Number of Participants
Marital Status	
Married	**6**
Single, Never Married	**5**
Single, Divorced	**3**
Separated	**-**
Common-law marriage	**1**
Widowed	**4**
Number of Children (average of 2.2)	
None	**5**
One	**1**
Two	**3**

Table 2 (continued)

Three	**1**
Four	**3**
Five	**1**
Six or more	**1**

Over half, eight of the study participants, reported being single and six reported being married, while one reported being in a common-law marriage. Of the single women, three were divorced and single. Four women who were either single or married who also reported being widowed due to their deceased husband dying of AIDS-related complications. In all of the married, divorced and/or widowed cases, the deceased spouse was the person that transmitted the HIV virus to the woman.

The average number of children the women had appears to be relatively low (2.2). All but one of the women reported to have been diagnosed during her child-bearing years. The women's HIV status may have resulted in the decision not to bear children, since at least eight of them were diagnosed after the birth of their last child. One of these women discovered that her fourth and youngest child was also HIV positive. Three women did have a child after their diagnosis and consulted with their treating physicians and were administered preventative medications to lower the risk of mother-to-child transmission. The five women who had no children stated that their decision was heavily based on their HIV diagnosis. Finally, the oldest participant (age 70) reported to have

been infected through a blood transfusion and was diagnosed at age 55 long after having had her five children.

Socioeconomic Factors

Table 3

Socioeconomic Factors

Variable	Number of Participants
Annual Household Income (average=$12,883)	
Under $5,000	**2**
$5,000 - $9,999	**7**
$10,000 - $14,999	**1**
$15,000 - $19,999	**1**
$20,000 - $24,999	**1**
$25,000 - $29,999	**1**
$30,000 and above	**2**
Number below the federal poverty level	**13**
Private Insurance	**3**
Uninsured	**4**
Medicare	**2**
Medicaid	**6**

The majority of the participants (13) meet the federal definition of living below the poverty line. It should be noted that although the majority (10) report annual incomes of less than $15,000, and many are mothers with children in the home who are dependent

on this income. The outliers that stand out are the two women who earn more than $30,000, and this seems to be consistent with their level of educational attainment as both have a college degree. Also noteworthy is that at least two women who are married and have children in the home meet poverty guidelines, even though they report a higher income level than some of their peers in the study. Finally, two women who report their income to be less than $5,000 are among two of the four immigrants who participated in the study. This further suggests that undocumented individuals living with HIV face additional struggles, especially financial hardships.

The majority of participants were either non-insured or under-insured with only three women who reported having had private insurance. The majority of under-insured (8) were covered by Medicaid and Medicare while the women who had no insurance reported immigration status which prevented them from being eligible to receive any type of assistance from entitlement programs, though their children did receive some benefits. Many of the women in the study reported to relying on the federally funded Texas AIDS Drugs Assistance Program (ADAP), under the Ryan White Care Act, that covered the expensive medications needed to treat HIV. The Ryan White Care Act is a series of grant programs that fund treatment services for people with HIV/AIDS who are either uninsured or underinsured; it is not a health insurance program like Medicaid or Medicare (National Health Policy forum, Sept, 2005). Once again, of the three women who reported having private insurance, two had higher levels of education and income.

It is important to compare these demographics with the most current Census reports due to the size of this study's sample. According to the Texas State Data Center (TSDC), Table 2 provides the estimates of the number and percent of uninsured by age and race/ethnicity for Texas Metropolitan statistical areas. For San Antonio the 2005 population was 1,889,810 and of those an estimated 303,044 (30.6%) Hispanics were found to be uninsured as compared to 98,871 (27.0%) Anglos and 43,765 (27%) Blacks (TSDC, 2005). These estimates are consistent with my findings in this small study sample of fifteen in that they can be compared to this larger data set found in the Texas State Data Center of the number and percent of uninsured by age and race/ethnicity.

Number of years living with HIV

Table 4

Number of years living with HIV

Variable	Number of Participants
Average Number of years living with HIV (average = years)	
Less than five years	**-**
Five to nine years	**1**
Ten to fourteen years	**12**
Fifteen to nineteen years	**-**
Twenty to twenty-six years	**2**

The majority, (13) women were diagnosed around the same time, in the early to mid-nineties (1993-1995), which is consistent with the time of a rise in number of heterosexual women identified as HIV positive. According to the National Institutes of Health (NIH), AIDS cases among women increased threefold from 1985 to 1996 (NIH, 1998). Also at this time, heterosexual women with no identified risk factors of their own were testing positive, leading to the argument that their male partners were placing them at risk.

Another important point is that the survival rate of people who tested HIV positive in this time frame referred to above have become known as "long-term survivors" due to the advances of medications and the introduction of the cocktail drugs in the late nineties (1997). In fact, the first protease inhibitor was approved in 1997 (thebody.com, 1997). The women in this study that were diagnosed in the early to mid 90's, have all had access to protease inhibitors.

Number of Years Involved with *Mujeres*

Table 5

Number of Years Involved with *Mujeres*

Variable	Number of Participants
Number of Years (average = 9.13)	
Less than three years	**1**
Four to seven years	**4**
Eight to eleven years	**6**
12 years or more	**4**

The original starting date of the support group offered at *Mujeres* was December 1, 1994. Three of the four participants that were involved with *Mujeres* for twelve years or more have been there from the beginning. Their longevity in the support group also suggests that they have found comfort in the support they received and the camaraderie that they experienced as being part of this group. It also speaks to the issue of finding a safe place where they can be themselves and not have to worry about stigma or discrimination due to their HIV diagnosis. Many of the participants voiced this sentiment in the interviews and referred to the support group as their "second family."

Strengths/Resources

Faith (Religion and Spirituality)

In all but one interview, participants referred to faith being central to their lives and to having a strong belief in a higher power. When mentioned, it was clear that this belief served as the primary source of strength in how they face the challenge of living with HIV. Twenty million Mexican Americans live in the United States. Eighty percent of the Mexican Americans in the United States are Catholic (Kane & Williams, 2002). It is vital that health care clinicians become familiar with and acknowledge the role of religion and religiosity on the health practices of Mexican Americans so that these needs may be addressed through holistic care (Lujan & Campbell, 2006). Most Mexican-Americans follow Christian faith, with the majority being Roman Catholic.

The qualitative researcher, Berry (1999) reported that Mexican American women accessing prenatal care frequently expressed feelings indicating that they saw illness as a punishment from God or as a purposeful, God-sent event (Berry, 1999). These individuals yielded complete control to God's will reflecting the view that they felt they had little control over their lives and must put their trust in God to keep them safe. Descriptors included phrases like: ''it's best to put it in God's hands'' and ''if it is God's will, I will heal'' (Berry, 1999).

It is important to point out that fatalism is a cultural belief that, like religion, can influence the way Mexican-Americans view their life. It is not uncommon to hear comments such as: "*Si Dios quiere*" (If God wishes) or "*Esta en las manos de Dios*" (It is in God's hands) which seemed to be fitting to the participants of this study. *Fatalismo* (fatalism) refers to a general belief that the course of fate cannot be changed and that life events are beyond one's control. In the health literature, fatalism usually is conceptualized as a set of pessimistic and negative beliefs and attitudes regarding health-seeking behaviors, screening practices, and illness (Abraído-Lanza et al, 2007). Cultural beliefs like *fatalismo,* the idea that whatever happens, happens: "I'm going to get diabetes like my parents and my grandparents" are factors to consider when working with Latinos who are experiencing a health problem (Foreyt, 2003).

When asked 'How have you lived with HIV?' Mary 1 responded: "I have a lot of faith in God." (Line 19) When asked 'What do you feel has helped you to cope?' Mary 1 replied: "I put it in God's hands and you know, I was not religious before, but I think

after this I really got more religious and I think I put it in God's hands… (Lines 106-107) She went on to say: "I think my faith in God…that really means a lot to me because I said I was born a Catholic and will die a Catholic…without God I would not be here so I wake up every morning and thank God that I am still here." (Lines 340-344) Mary 1 described how she rationalized losing her job when her boss found out she was HIV positive: "It worked fine because you know, I was able to take care of him [her husband], lost my job and so I guess when God closes one door, he opens another." (Lines 57-58)

When Blanca spoke of the sudden death of her 19 year old son, she stated: *El (Dios) sabra porque se llevo a mi hijo primero, no se. Y lo tengo que tomar asi, como que un dia lo voy a ver yo a mi hijo, voy a estar con el. No pudo decir que muy pronto, porque solamente Dios le quita la vida a uno.* Translation: Only He (God) knows why he took my son first (before me), I don't know…And I have to think about it in that way, like if one day I am going to see my son, I will be joined with him again...I cannot say that it will be very soon, because only God takes away one's life. (Lines 84-88) This rationale seemed to help Blanca reach a level acceptance concerning the untimely death of her son. In reference to the question of what gives her the strength to go on living, Blanca responded: *"Pues, las unicas fuerzas que me da, es Diosito. Es mi fe en Dios. Si, es mi fe en Dios, y yo digo que este, si Dios me quita la vida, no es por mi enfermedad que me la esta quitando, si no es porque Dios, les da a uno lo que se merece uno, y Dios lo tiene hasta el dia que ya esta persona ya no lo quiero aqui, y me lo llevo porque, me la llevo, es mi hija y me la tengo que llevar." "Solamente Diosito que nos dio la vida, y El*

que sabe que dia nos va recojer." Translation: Well, the only sources of strength I am given are by God. It is my faith in God. Yes, it is my faith in God, I say that if God takes my life, it is not because of my illness that he is taking my life away, it is because God gives one what one deserves, and God has us here until the day that this person… [God says: I don't want him here and I am going to take him because…I am going to take her, she is my daughter, and I have to take her] (Lines 101-106). Only God who gave us life, and He is the one that knows the day he will come for us. (Lines 124-125). It is interesting to note that Blanca placed her destiny and that of her loved ones "in the hands of God". Her philosophy on life in general can be described as fatalistic.

Blanca further explained that the reasons she is doing so well and that the medications are working so well is that 'God has made that possible'. She stated: "Si, este…gracias a Dios, siempre estoy…indetectable, estoy muy bien. Ya tengo como unos uh…siete años que estoy indetectable. Y estoy con mis pastillas desde el '98 que me detectaron mi…mi virus…este, no he cambiado pastillas nomas que dos veses. Y espero no, no cambiarlas, que me sigua ayudando Diosito con estas pastillas que el me puso. Translation: Yes, thanks to God, I am always undetectable, I am good. It's been like about seven years now that I have been undetectable [referring to her viral load]. And I have been with my pills since '98 when I was diagnosed, with my, my virus, I have not had to change my medications except for two times. And I plan on not changing them, and that God will keep on helping me with these pills that he has provided me. (Lines 128-132)

When Elisa was asked to identify her source of strength, she responded: "… God. "I turned to God first. My strong faith in God." (Lines 53 and 54) "It hasn't really affected my faith, [her HIV diagnosis] if anything it's strengthened it." (Lines 80-81) When asked if she had a message that she would like to send out, she replied: "Everybody has a life that God gives you and that's what you have, that's what you're going to make of it. It is what you make of it. So to me, my life has been perfect. I wouldn't change it, I would still marry him, [husband] I would still have my kids." (Lines 430-433) Elisa seemed to justify her life with her husband, her HIV diagnosis, and becoming a mother to predestination in accordance with "God's plan".

During the interview the topic of writing as a therapeutic tool came up and Elisa stated she would like to leave something for her kids. She stated: "For when I am not around when God decides that…That's [a journal] as good idea!" (Line 502) Elisa's comments in reference to her faith can also be viewed as an example of how many Mexican Americans use *fatalismo* as a way to justify their destiny in life.

Similar to Blanca and Elisa, Minga also seemed to believe that her destiny is predetermined by God when she stated: "God is going to keep me here until he gets ready to take me. I am not going to die until God takes me. God is the only one that's going to take me when He gets ready. (Lines 61-62) When asked what gave her strength and if faith was important to her, Minga responded: "Faith is very important for all of us to have whether you have the virus or not. (Line 358) Because without God… (Line 362) …my grandma always told me everything I do ask God for it and God will give you the

strength. And God is the first one we should always put and keep our faith by being strong or whatever we are going through in life…it's the 'Man" upstairs that's going to keep us going. (Lines 362-364) …Never question God. (Line 376) This suggests that you accept what life brings as it is predetermined by God, and therefore should not be questioned.

Monica explained why she thinks she has been so healthy since her HIV diagnosis as being related to her mission in life. She stated: "Whatever God has in store for me or planned, um…I've been able to do it. And I'm very blessed that I can and I will continue to do whatever I can to help the community and help someone else." (Lines 149-151) "I know I have a lot of faith because, I mean, you know, God works in mysterious ways and prayer just works, you know." (Lines 327-329)

Delilah explained the importance of faith in her life: "Faith. It's like my foundation because my…whatever else is going on in the world, whatever else if going on in your life, that's basic…it's like breathing…you need it…I believe in the higher power and that's what does it…From there everything starts. From there everything takes place." (Lines: 206-210)

Mary 2 discovered that faith was what was going to help her cope with HIV. She explained: "Oh yeah, I realized then that that's what was going to help me cope with everything, was to deepen my faith in God. And uh, I talked to Gabby [her husband] about it a long time. …we get up in the morning, and get a cup of coffee, we'll go outside in the back porch, we'll talk about things, and that's one of the things we talk

about. You know, that how, our faith has gotten us through all of this. And we both believe strongly in God, we both believe strongly that He has led us through everything we've gone through. And He has been by our side all the time." (Lines 332-338)

Christina explained how she coped with her HIV diagnosis: "You know, the coping and dealing, and you know what's gotten me through this? That would be one aspect of it. And I'll tell you the second part for me, the coping process, is my faith…my faith…to a T." (Lines 242-244) "…my faith sits on everything." (Line 757)

Monica, Delilah, Mary 2, and Christina all addressed the importance the role of faith plays in their lives as described in the quotes above. It is their foundation and what they report to have given them the strength to cope and go on living with HIV.

Children/Family and Significant Others

Of the two-thirds of the study sample who are mothers, all spoke of how their children were a source of strength for them and how they have fought to live with HIV in order to see their children grow.

Sylvia stated that her youngest child [daughter] was her strength. "… I know that…that I got to be around for her. (Line 400) She's my strength right now. My main goal and strength is my daughter. To be around to see her stand in her first *quinceañeara*." (Lines 405-406)

Dora claimed that her daughters were her motivation. "*Mi motor son mis hijas y por ellas yo tengo que tener valor para seguir y luchar y salir adelante. De no caerme y*

si me tropiezo, volverme a levantar por ellas." Translation: My motivation is my daughters and for them I need to have the courage to continue to fight and come out ahead. That I not fall… and if I trip, I need to get myself up for them [daughters]. (Lines 301-303)

Blanca stated that the way she lives with HIV is realizing that she has children for whom to live. She claimed: "…*viendo que tengo hijos, por quien viver*." Translation: I look at having children for whom I have to live. (Lines 20-21)

Maria recalled that her motivating force to continue to live after her HIV diagnosis was a strong sense of anger and a strong will, and that now that she is a mother of two healthy babies, she cannot give up that will to live. In her own words, Maria expressed this sentiment by saying: *"Si no tengo corraje, si no tengo fuerza, no…I'm just going to give up. Y ahora yo no puedo. Tengo mis hijos."* Translation: If I have no anger, if I have no strength, no, I'm just going to give up. And now I cannot. I have my children." (Lines 239-240)

Elisa claimed that what helped her to cope with her illness was: "My children, the needs that they have, I have to ignore mine. So I have to snap out of it, I have to, and it's hard…but the kids…It's the kids…It's Gabriela too, I can't just stay stagnant, I have to move on. So I think that it is my children, my children's needs" [that help her cope]. (Lines 88-92)

Christina, a forty year old Mexican American living with HIV is the mother of two daughters, one of whom is also living with HIV states: "…my kids are my world." (Line 375)

Minga explained what motivates her to want to live when she stated: "I'm fighting the disease. I want to live because I have kids. So that's the word I use, 'fighting'. I am fighting against the virus." (Lines 73-76) … "And my grandbabies, that I love. That keeps me energized. Instead of letting the virus take control of me, I'll look at my family that really needs me"… (Lines 82-83) "Right now, that the way I'm fighting the virus is because I'm trying to find my two boys, they were taken from me. I've got my two girls that are grown but my two little boys I haven't seen since they were four and five, and that's what is making me strong, to fight the virus and not let myself die until I find my boys." (Lines 90-93)

Participation in Mujeres' Support Group

All fifteen participants have participated in the support group offered by *Mujeres Unidas Contra el SIDA* at one point in their lives since learning of their HIV diagnosis. Some of the responses on how the group has helped these women cope after discovering their HIV diagnosis were similar. They all had something positive to say about their involvement in the support group, for example:

Mary 1 states: "The group was founded on December 1, 1994 and it started with four women, two positive and two negative. I was one of the positive ones and it was

really hard that day because when we started we did not know who was positive." (Lines: 213-215) She goes on to describe the first group meeting that was held at *Mujeres.* "And I did not know anybody that had this and I thought at the time that my husband and I were the only ones that had it, but I got to meet other women, one by one. It was awesome, it was neat to share. We hardly talked, but we hugged a lot I remember, and then after that every week, every week…it has been part of my life." (Lines 217-221)

When asked if other agencies offered support group services similar to *Mujeres*, Mary 1 responded: "Oh, no. There are a lot of women out there that still don't go to support groups and it is really sad because there isn't any out there. …right now I think we are the only ones that are basically for Hispanic women and it is tough and there are a lot of groups out there, but I have been to other support groups just to visit and it is not the same. It is not the *familia*, like we have… you know some of us come to group and if want to get a break you can take off and come back and you are still welcome like you just left yesterday. So you know, I think that is what makes us unique that we're… even though we might have not seen you for a month...we call each other or we are in constant contact with each other…we have a little core group that is constantly together all the time, you know, if we do anything outside of the office we tell each other and we spend a lot of time together." (Lines: 247-257)

Mary 1 summarizes her comments about being a member of the *Mujeres* support group by stating: "I don't think I could join any other group. This is the only support

group that I know that I would be comfortable at and I feel sorry for all the people that are not in support groups because they need to, they need to be." (Lines: (280-282)

Monica refers to how the *Mujeres* support group helped her by saying: "And then um…and then the support group that I encountered, you know, when I was newly diagnosed after putting it off a year. Hmm…being able to just meet other women… because, you know, you think you can conquer it all and you have a positive frame of mind and you know it's [HIV] not going to stop you but there was something missing (referring to the *Mujeres* support group) and it was just meeting other women…You know, just by being there, you know a voice and talking about… you know, our different experiences. It helps…it helps so… you know, and having a good leader from that group." (Lines: 92-99) Even though Monica took about a year to join from the time she learned of the *Mujeres* support group, she explains her positive experience: "…and I tried it and uh… you know it was totally what I did not expect a support group would be about so… (Lines 109-110)

Dolores describes her experience as follows: "Yes, I mean we feel more comfortable because at least we all have the same thing and we talk and we feel more relaxed and more comfortable talking to others. (Lines: 102-103) She describes the positive feeling she has when she attends a group session at *Mujeres:* "That when we get out, when we come to women's group, you know we say that we are somebody! And I even grab my arms and I hug myself and I say I love myself, I love myself, and " I AM somebody!" (Lines: 237-239)

Becky summarizes what helps her to cope with HIV on a day to day basis: "The support that I've gotten from friends, from the support group from *Mujeres,* from a couple of family members whom I can talk to openly with and you know…they listen to me." (Lines: 156-157) At the time of the interview, Becky was just coming back to attending the support group and working as a *Madrina* (Peer Educator) and she was clearly planning to get more involved as this involvement as she described was a way to help her stay focused and prevented her from becoming depressed. She states: "My goal now is to get back to the way I used to be. To go back to being involved in these meetings and stuff that I used to go to, because I realized that's what kept me going, that's…I looked forward to all of that and I miss all that and I want to go back and I want to get back involved and do you know what I love to do the most, which is go out there and be an advocate and to gain more knowledge and…" (Lines: 358-362)

Elisa recalls her participation in the *Mujeres* support group when she first discovered that she was pregnant and HIV positive. She explained the impact it had on her life by saying: "And…oh my God, it was like another family I had that was really there for me all the time and my husband wouldn't go (referring to the family group sessions). He didn't want nothing to do with it, because he is very, very private. I needed to do it for myself... for my sanity… I just needed to do something and the group it wasn't called *Mujeres* at the time, it was amazing. It just pulled me in and took care of me, for that year, and I'm sorry that I left them." (Lines 59-63)

Blanca speaks in more general terms of the importance of support groups while referencing her participation in the *Mujeres* group when she says: *"…muchas vezes tambien, los uh… grupos de apoyo ayudan mucho a salir adelante con esta enfermedad porque es importante tener con quien platicar sobre esta enfermedad,* y*…"* Translation: Also, many times, the support groups help to come out ahead with this illness because it is important to have someone to speak to about this illness, and… (Lines 107-108)

Barriers/Stressors

Disclosure

HIV positive women often do not reveal their diagnosis to current or possible sexual partners, to close friends, or to potential employers because of the stigma attached to the disease, according to a survey released by amfAR in March, 2008 (Krouse, 2008).

One stressor that women who were mothers had to contend with was when and how to tell their children about their HIV status. The most common concern expressed by women with children was the fear of disclosing their HIV status because it might cause a negative experience for their children due to the stigma and possible discrimination related to HIV. For example, these children may not be allowed to play with others whose parents may fear transmission due to a lack of education about HIV/AIDS. As a result of this fear, the mothers displayed a tendency to want to protect their children from any potential harm and discrimination and thus grappled between informing and thus teaching their children about HIV/AIDS or deciding to stay silent.

Elisa expressed concern about the repercussions her twelve-year-old son and five-year-old daughter may experience if she and her husband tell them about their HIV status. In describing her struggle with telling her son, she stated: "This is the way I see it. He (her husband) sees it as it would crush his (her son's) self-esteem. It would… he would have that stigma that people have. So he is afraid that it would affect him...we don't want to push him to grow ahead of his time."(Lines: 279-286). Elisa appeared to be struggling with what she might think is right for her children in terms of disclosure and what her husband thinks. They may need to work this out before they approach the subject with their children so that they can give a consistent message when they decide that the time is right.

Another mother of a nine-year-old girl, Sylvia, expressed her thoughts on disclosure when she stated: "We think…I mean, she's bright, but we still don't think she can under…grasp it all yet. As she grows a little older, we'll eventually get to it…we'll tell her, let her know exactly what's going on. Because she…she gets some, but she doesn't know it all. (Lines: 295, 302-303). Sylvia seemed to think that her daughter may have suspected that she was HIV positive, but did not want to come out and talk about this due to what appeared to be Sylvia's fear and doubt that her daughter could handle this.

Dora, a mother of two daughters (ages 6 and 11) suspected that her oldest may have had an idea about her HIV diagnosis and stated: *"...yo se que ella tiene tal vez la idea pero nunca me ha hecho preguntas. Y hasta ahorita se lo agradezco que no me*

pregunte, porque como son mis hijas, alli si no se que voy a hacer" Translation: "… I know that she has an idea, but she has never asked me any questions. And until now, I appreciate that she has not asked because since they are my daughters, I do not know what I am going to do." (Lines: 270-272) Dora later expressed her fear of losing her daughters if they know and might not understand. Dora was infected when she had a blood transfusion in Mexico after the birth of her daughter. Her husband is HIV-negative and has been supportive of her since her diagnosis. Though she was not infected due to any high risk behavior, Dora expressed her fear of being judged for being HIV-positive because of the stigma associated with this disease.

By far the most common reason for not telling was fear of rejection. Most of these women already have multiple challenges to their self-esteem (poverty, poor education, unemployment, discrimination, and so on) and are unsure of their worth. Many simply believe that the presence of a progressive, life-threatening, often disfiguring, communicable disease makes them unlovable and unacceptable (O'Connor, 1997). Some of the participants of this study were found to have experienced a fear of rejection and a low level of self-worth.

In describing why she has chosen not to tell her family, Christina stated: "My immediate family, I love them to death but this is…uh, uh, something that, and it isn't anything that I'm afraid they're going to do…I'm going to become the leper… (Lines 145-147) Rebecca described how she felt after her diagnosis and stated: "It was hard, umm…at one point I thought I was worthless, umm…I had no hope, I just didn't want to

be around anymore." (Lines 438-440) Dolores recounted the affects of the physical and verbal abuse she encountered as a child. She stated: "All my life, I've been suffering…just like a dog…I used to say, I ain't nobody"… (Lines 234-235)

All the mothers who were quoted above decided to postpone telling their children until "the right time." In some cases, the children later discovered the truth and confronted their mothers, asking why they were not told. For example, Sylvia's adolescent son "…found out through somebody else. While in a sex education class at school, a man was talking about having HIV and he held up his medication bottles. Well, my son recognized one of those bottles. And that's when he came home and he told me, 'How long have you had it?'(referring to HIV) And I go, well, what makes you think I have HIV? And he went to the bathroom and he pulled out the medicine and he goes 'A man at my school has one of these bottles.' And that's when I told him." (Lines 331-336) This was the impetus for Sylvia to sit both her sons down and tell them of her HIV status. They are both grown now and provide emotional support to their mother. However, she reported her intention of continuing to withhold this information from her daughter until she decided when the "time is right".

Instead of actively dealing with the situation, HIV-positive women who struggle with disclosure often anxiously wait for an accident to happen. They hope that someone close to them will find their medication or take a medically related phone call that ends the secret keeping (Goggin & Rabkin, 1997). Such was the case with Sylvia. She said

she felt "relieved" once she was confronted and thus forced to disclose her HIV positive status to her sons.

Another point to highlight is that children are resilient and parents often underestimate their children's capacity to understand. For half of the twenty-four of the children whose mothers took part in this research study, twelve encountered other levels of stress like separation from their mothers, as well as overcoming challenges such as poverty and homelessness. The resiliency level of these families appeared to be at a peak and therefore may have aided the children in accepting the disclosure of their mother's HIV status. When children are told about a family member's HIV-positive status early and repeatedly, they have the best chance of adjusting to and effectively dealing with the situation. Most children, when given the chance, adapt to the worst of situations. Conversely, children struggle to understand deathbed explanations and postmortem stories of a missing parent (Goggin & Rabkin, 1997).

Similar to the mothers' concerns of disclosing their HIV positive status to their children, other participants spoke about not wanting to disclose to family members or friends. Mary stated: "My sister. I told her immediately…My parents both passed and I never told them. I never told them because they were up in years and I did not want them to worry about me or get sick." (Lines: 114,126-127) Mary was protective of her elderly parents and did not want them to fall ill due to a disclosure. She also shared that she was afraid that they might blame her husband and accuse him of knowingly infecting her.

Maria and Luis, a discordant couple, a pair of long-term sexual partners in which one has a sexually transmitted infection and the other does not, in this case HIV struggle with the issue of disclosure (Medicine Net, 2004). With the support of her husband, Maria who is HIV positive, decided to get pregnant and subsequently delivered a set of twins who are HIV negative and very healthy. In discussing her current struggle with disclosure, she stated: "Well, the fact that I cannot…he [her husband] does not want me to disclose to his family, it's more of a problem and I don't disclose to my family either. You know, only part of my family knows. Still, it's hard having to hide the medicine or not being able to go full time to visit them [in Mexico] because I have to come home to the doctor and don't have to give any explanations. You know, it's really hard." (Lines 152-156) Maria feels that she has to hide her diagnosis from both families. She would like to tell all of her family, but she and her husband have yet to reach an understanding of when to disclose to both families. It seems that her husband is fearful that his family might reject Maria as they have only been married for a short time and may not approve of their marriage.

Rebecca, a mother of four, who discovered she and her husband and their youngest daughter all had HIV, shared her thoughts on disclosure. She stated: "…not everybody that I talk to knows. And my close family members, like brothers and sisters, they know. But out of that circle except for one cousin, they don't know." (Lines: 187-188). "You know, because you tell somebody who you think is your friend and next thing you know, they no longer want to speak to you or having anything to do with you."

(Lines: 208-210) "…a friend of mine whom I had been talking to for a while and um, I would tell him anything and everything, except that, I just didn't know how. I'd just say 'okay, it's not the right time. It's not the right time.' And then when I thought it was the right time, and I did say he stayed for a while, like as far as the friendship and being there and talking on the phone and I never heard from him no more." (Lines 214-218) Rebecca described the risks that HIV-positive individuals take when disclosing to family and friends. There is that fear of the unknown, with questions such as, what is the reaction going to be from the receiving party of this news? Will they remain friends? Will they abandon the friendship and have this be another loss in their life for the person disclosing? In Rebecca's case, her relationship ended abruptly when she took a chance and confided in her male friend.

In most cases of adults not wanting to disclose to family members, there rests the fear of being judged and ostracized. The women whom I interviewed and who were struggling with disclosure to family members mostly reported being fearful of how family members would react. In addition, they shared that they feared the possibility of being rejected by loved ones.

Some participants reported that to their surprise, the fact that they were HIV positive was disclosed for them, meaning someone else revealed their status, thereby involving a breach of confidentiality and how this in turn led to a form of discrimination.

Mary 1 was devastated when she learned that her husband was infected with full blown AIDS after an extended hospitalization. Two days after learning that her husband

had AIDS and asked to be tested for HIV, she received the news that she had tested HIV positive. To further compound her situation, Mary's older brother went to the hospital to visit her husband. He ran into an old friend who told him the floor where his brother-in-law was on was exclusively for AIDS patients, thus alerting Mary's brother of her husband's HIV/AIDS diagnosis. Mary 1 recalls this incident vividly as she shares her thoughts: "My brother found out from the hospital. Some guy who was working there told him. I saw your sister here. Did you know that the guy she is visiting, [he did not know who he was], has AIDS? My brother was WOW, you know. But he never told me that he knew. Years later, I think like 5 to 6 years later, we were having a conversation and I decided to tell him. He said I already know, so I never felt any judgment from him. He has always accepted me. My nieces and nephews know, and my older sister knows." (Lines: 127-132) The clear breach of confidentiality took place when the hospital worker told Mary's brother that her husband had AIDS. This is another illustration of how families can keep secrets for a long time and then the truth surfaces later. Mary 1 found that her brother was aware of her diagnosis and was there for her but she lived for all those years not knowing how he would react. Another point to consider is that silence may be related to cultural norms that pose barriers to utilizing resources. Cultural beliefs and perceptions may influence the extent to which some Hispanics access mental health services (Green, 1999; Malgady & Sayas, 2001; Sue, 2006).

No matter what decision is made to tell or not to tell, the process of preparing to disclose is stressful. This decision is an individual's choice and the person can ask for

help and support during this process. With the women I interviewed, it seemed that disclosure was just one more stressor to worry about and since the reaction of those told could not be pre-determined; ultimately, the majority of the women felt they were taking a risk. In some cases, keeping a person's HIV diagnosis secret may cause more emotional distress than what being rejected will provoke. It is also important to note that women may place themselves at risk for domestic violence when disclosing to an intimate partner. A study revealed that over one in five women with HIV had been physically harmed since their diagnosis. Of these, almost half reported that they felt that the physical aggression resulted directly from their HIV status. Even if a woman never faced domestic violence before, she may encounter it after her partner learns she has HIV (Trisdale, 2005). It is recommended that when a woman feels like she may place herself at potential risk for violence, she should involve a third party to ensure her safety. In the case of the study participants, most have other issues that seem to take precedence in their daily lives in terms of survival. Therefore, it can be concluded that these women dealt with the issue of disclosure as just one more thing to live with; this is evidenced in the resilient manner with which they tackled their life challenges.

Stigma & Discrimination

The stigma related to HIV disease is closely tied to why a person does not want to disclose his/her status. HIV positive women in the United States face strikingly high levels of stigma. According to survey results released by amfAR, The Foundation for

AIDS Research: "Despite 25 years of progress in diagnosing and treating the disease, one in five Americans would not be comfortable with having an HIV positive woman as a close friend," according to Susan Blumenthal, senior policy and medical adviser for the American Foundation for AIDS Research (amfAR, 2006).

AIDS-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. They can result in begin shunned by family, peers and the wider community; poor treatment in healthcare and education settings; an erosion of rights; psychological damage; and can negatively affect the success of testing and treatment (www.avert.org/aidsstigma.htm).

Dolores described the struggle she has had in disclosing her HIV positive status to her brother with whom she shares a home. She stated: "No, he doesn't know nothing. It's hard. I mean I go through hell because sometimes I wanna tell him. But sometimes I don't. He's probably gonna run me off." Dolores lives with the fear of her brother reacting negatively and throwing her out, which will result in becoming homeless. Dolores goes on to further share her worries that if she does disclose her status, she will further be stigmatized by a general lack of knowledge about how the virus is transmitted. "Because he's gonna think he's gonna get it by drinking out of a glass of water or sharing the same plate or…eating with the spoons that we use. He's got his own bathroom. I got my own bathroom. But sometimes, you know he goes and uses mine. But what if he knew I had HIV? He's gonna be cleaning up after me after I get anything." (Lines: 71, 75-76, 78-82) The lack of education on how the HIV/AIDS virus is transmitted is

unfortunately a contributing factor to negative reactions from family and friends. Oftentimes, it takes someone in a family to test HIV-positive before the family begins to educate themselves on the modes of transmission and how HIV cannot be transmitted by casual contact.

Sylvia recounts a negative experience where she felt discrimination by her brother. "When we went over to have a birthday party for my nephew he gave everybody, you know, special party cups and everything, but he had given me a Styrofoam cup so I could throw it away. He made sure my plate and everything didn't touch anybody else's plate. This is my brother who works in the medical field who is very naïve…I think this was the worst experience I ever had." (Lines: 179-185) Again, this type of discrimination can be avoided by better educating family members on the risks of acquiring HIV.

Dolores, who suffers from major depression, recalls an incident that occurred at a party she attended. "Yes, recently I went to a friend's house and they were talking about people with AIDS. They said: 'I don't want any of them to come to my house and sit on my commode. If they have HIV, I don't wan'em because I'm gonna get it, I'm gonna get that disease.' That makes us feel down, sad and hurt and blue and hurt." (Lines: 84-87) Though this can also be viewed as another example of a lack of education about HIV/AIDS, it still results in the HIV-positive woman feeling like she would be discriminated or shunned if her friends knew she was living with HIV. These perceptions

will continue until there is a better understanding of the disease and the risks of transmission.

Depression

Depression is often found to be a secondary symptom of an HIV diagnosis. Hopeless, depression, and suicidal ideation are common reactions to being diagnosed with HIV infection (Jenkins & Coons, 1996). Some people may already be prone to depression and others may become depressed as a result of their HIV status. It is estimated, for example, that 78% of HIV-infected individuals diagnosed as depressed had a history of depression prior to HIV infection diagnosis (O'Connor, 1997). Depression is more prevalent among women with HIV. In fact, studies show that almost 60% of HIV positive women display clinical signs of depression and up to 75% display at least some type of depressive symptoms. HIV positive women are 20% more likely to be depressed than HIV positive men (Margolese, 2003).

Of the fifteen participants, eleven reported to have suffered from depression at some point after their diagnosis, nine reported to have undergone treatment with medications and five admitted to having contemplated suicide. These are some of their stories:

When asked the question "How have you lived with HIV?" Dolores responded: "Well, I go through a lot with depression, stress. And, ah, when I first learned that I had HIV, I wanted to commit suicide." (Lines 21-22) She explains that the depression has

been so bad that she has not been able to eat. She is currently taking prescribed medications for the depression and is seen on a regular basis by a psychiatrist. Dolores admits to having a history of depression which she believes to have worsened after her HIV diagnosis. This is true of other women who report to be treated for depression as previously discussed.

Sylvia stated that she needs to take her medications like they are food because she does not want to go "back to that dark hole again." (Lines 28-29) She describes that "black hole" as a time when she was "out of commission" and in "heavy denial." Sylvia stated that she did not want to know about "it" (HIV) and didn't care to know about "it". She reports to taking care of everybody but herself. She has also been on anti-depressants since she was diagnosed with HIV and also admits to having experienced suicidal ideation.

As mothers, infected women are central to providing care for their infected and uninfected children. Infected women are often affected by HIV/AIDS both as caregivers and as receivers of care. As caregiving mothers, infected women often have a difficult time tending to their own needs (Campbell, 1999). HIV-positive mothers don't often get enough practical support (including baby-sitting) or encouragement from friends and relatives. Caregiving demands often interfere with a woman's ability to seek and receive adequate care. They are often single mothers with more than one child. They live with other chronic stressors related to poverty, fragmentation of family, or child behavior problems (common in both their HIV-infected and uninfected children). Claude Mellin

and Anke Ehrhardt examined caregivers' needs in a study of twenty-five African-American and Hispanic families in New York City with at least one HIV-positive child. (The caregivers were either the biological mothers who were HIV-positive themselves, or foster parents who were not.) Compared to foster parents, the HIV-infected mothers reported more social isolation, more financial problems, and perhaps most urgent, too little respite from child care (O'Connor, 1997). Therefore, it is clear that HIV-positive women have a lot going on and when they put themselves last on the priority list, they often neglect themselves. This can negatively influence their well-being as well as their physical health and can bring on depression.

Delilah admitted to "having a lot of depression problems, bipolar, and manic depression, but [she tries] not to be too dependent on medication." (Lines 56-58) She has been hospitalized on more than one occasion for experiencing suicidal ideation. In fact, upon first learning of her HIV status, Delilah attempted suicide. "I was diagnosed one week and by the end of that week I was in the hospital. I was…I couldn't handle it, so I ended up in the hospital, in the emergency, and I had taken a bottle of sleeping pills, I remember." (Lines 98-100) Delilah has a number of challenges in terms of her mental health and has had to be hospitalized more than once. She admits having stopped taking her medications, which can lead to an imbalance and almost always results in a hospitalization.

Minga stated: "When I first found out I had HIV, I wanted to kill myself, which I almost did, but I lived. (Line 23-24) So the way I tried to commit suicide, that's what I

said I tried to hurt myself, I tried to kill…strangle myself because I was hating myself because I would always say that would never happen to me. I would never get that virus." (Lines 37-39) Minga concluded that the reason she considered ending her life was because she did not think that she could get HIV and when she discovered she was HIV-positive, she did not want to even think about it since she had survived so much in her life, she could not believe that this was possible. Minga is classified as borderline mentally retarded (self-reported). She reported an extensive history of physical and sexual abuse. She was removed from her family along with her siblings at a young age and just recently reunited with her mother and some of her siblings after years of separation. Minga had several suicide attempts even before she became aware of her HIV diagnosis. Her immediate reaction upon learning that she was HIV-positive was to do what she had done in the past when confronting other life challenges. She attempted to take her life in an effort to end the pain.

Maria, who was diagnosed with HIV at the age of eighteen, responded to the question: "How have you lived with HIV?" by stating, as she begins to cry that "for most of the time, I haven't…" She goes on to explain what she means by this statement. "Well, it was like I was dead for a long time." (Lines 27 and 29) This is how she described her bout with depression after learning of her status. She explained that at that time of her diagnosis in 1992, an HIV diagnosis was thought to be a "death sentence" and since her husband had just proposed, she thought it was the end of her life.

When Rebecca was asked the same question, "How have you lived with HIV?" she responded: "You know there are days when I'm depressed, there are days when I don't feel sociable at all." (Lines 33-34) "…when I first found out I didn't want to do anything. I didn't want to talk to anybody. I didn't want to deal with anything at all. I didn't want to talk. I didn't want to eat. I didn't want nothing. I just wanted to be left alone." (Lines 39-41) "I was already depressed before because of, you know…things that happened in my life as far as family members. I guess through the years I was diagnosed with severe major depression." (Lines 73-75) Rebecca describes the classic symptoms of depression and shares that she had already received a diagnosis of severe major depression from a psychiatrist before learning she was HIV-positive. So she claims to have been aware of her symptoms and therefore knew she had to seek help. She joined the support group and reported to have found "a second family" where she was accepted for who she was.

Blanca described the moments after she was informed that her husband was in the hospital dying of AIDS related complications. She stated: *"Cuando me dijeron, que mi esposo estaba enfermo de eso, quise, yo queria matarme, queria tirarme del piso nueve. Pero estaba un amigo mio que me dijo que voltiara hacia tras y que viera que tenia yo hijos por quien vivir. Y por mis hijos es que he luchado y he tratado de salir adelante."* Translation: "When they told me that my husband was sick with that (AIDS), I wanted to…I wanted to kill myself, I wanted to jump from the 9th floor. But a friend that was with me told me to look back and to see that I had children that I had to live for. And

because of my children, I have fought and tried to go forward." (Lines 41-44) This seems to be a common reaction to finding a reason to go on living with a more positive attitude. Living and caring for their children becomes a motivating factor for women living with HIV/AIDS in not giving up and continuing despite their prognosis.

Elisa stated: "The beginning was rough, very rough. I felt like I died for a little while there…You guys (*Mujeres* support group) were like the first, it was like…you saved my life, because I thought I would die. But, I have had some hard times. Depression has been the main problem for me. My health has been okay. It's the depression that I can't get rid of. Most of the time, I try not to think about it." (Lines 23-26; 28-30) Elisa was pregnant at the time of her HIV diagnosis. According to Elisa, this was a time when she should have been full of life and joy but instead she reports to have been cheated out of that experience because all she could think about was death and was not able to focus on the new life she was bearing.

Alejandra stated: *"Actualmente estoy en un estado muy depresivo, muy estresante, a pensar de que tengo la oportunidad de tomar medicamento y de tener una persona que me quiere mucho. (una pausa) No hay manera de sentirme feliz. (una pausa) Realmente no puedo terminar de pensar lo que tengo. (una pausa) En lo que voy acabar, no quiero (pause) que nadie vaya a batallar conmigo en un futuro."* Translation: "Actually, I am (currently) in a very depressed state, extremely stressed to think that I have the opportunity to take medication and to have a person that loves me so much. (pause) There is no way to feel happy. (pause) Realistically, I cannot stop thinking of what I

have. (pause) And to know how I will end up, I do not want anyone to be troubled with me in the future." (Lines 29-33)

And lastly, Dora stated: *"Pues, si me deprimo a veces. Tengo días que a veces tengo que tomarme medicamento pero yo sola lo he dejado. Nadie me ha dicho que lo deje. Yo sola lo he dejado porque no quiero depender de medicamentos para la depresión. Porque es algo que yo puedo manejar, mi mente."* Translation: "Well, I sometimes get depressed. I have days when I sometimes I have to take medication, but I have taken myself off them. No one told me to stop taking them. I discontinued taking them myself because I do not want to become dependent on medications for depression. Because it is something that I can manage, my mind." (Lines 199-201)

Some studies have demonstrated a higher lifetime prevalence of depressive orders among the HIV population compared to the general population (Bialer, Bluestine & Richards, 1997). Other studies have described the effects of PWHIVs (Persons with HIV) living with a chronic disease. Several of the symptoms of depression seen with HIV infection are similar to those seen with other chronic diseases such as cancer, heart disease, or Alzheimer's disease. Although PWHIVs may share some of the same concerns – such as the prospect of debilitating disease, loss of financial resources, of early death – HIV-related conditions additionally elicit fear and stigma from the community at large (Ostrow, 1997).

Many factors contribute to the high rate of depression among HIV positive women. Experts believe that lower household income, active drug use, alcohol use, and

sexual and physical abuse may all add to the risk of depression. Relationship status and social support may also be related to depression (Margolese, 2003). There are many contributing factors that are directly related to the high levels of depression found among the study participants interviewed which is evidenced in their lived experiences. Individuals with psychiatric problems prior to infection are more likely to have them after infection. The most severe problems will usually occur among this group (O'Connor, 1997).

It is important to note the precursors of depression that these women may have had prior to their HIV diagnosis. For instance, most of the participants were poor and lived below the poverty line before they discovered their diagnosis, which can induce stress and lead to depression. A history of family dysfunction could also be identified as a precursor. Poor intimate partner relationships could also add to the possibility of having suffered from depression before the HIV diagnosis. A history of intimate partner violence of past child sexual abuse might be a precursor of depression. The fact that a high number of participants are survivors of family violence may be related to why so many report to have suffered from depression.

Findings revealed that when the participants of the study were asked how they coped and made meaning of their HIV diagnosis, they described other life-changing lived experiences that also induced stress but as a result of these experiences made them stronger and more resilient to better handle life with HIV. As expected, some of the common themes are interrelated and were expressed by several of the participants. In

examining the overall theme of *Barriers/Stressors*, issues such as disclosure, stigma/ discrimination, depression, were reported. Some unexpected findings included past traumatic life experiences such as child physical and sexual abuse, incest, rape, domestic violence, comorbidities, and the need to make their lives as "normal" as possible. These topics were raised during the interviews which had an impact on the majority of the women in this study in identifying their individual struggles.

Unexpected Findings

Another startling finding of this research was the high incidence of past traumatic incidents experienced by the women of this study, i.e. child physical/sexual abuse, rape, and domestic violence that is interrelated to the high incidence of depression. Of the fifteen respondents, at least ten have had one of these past traumas. Here are their stories:

Other Past Traumatic Life Experiences, i.e. Child (Physical and Sexual) Abuse/Incest, Rape, and Domestic Violence

Rebecca recalls having been the victim of domestic violence for almost two years before escaping from this situation. She says: "I've gone through…I guess basically, things that I didn't…never thought I would go through as far as uh…being physically abused, verbally, mentally, and it was hard for me and it's still hard for me. It's still because I've seen my sister go through it before and I've seen other people go through it and I still see people in my family that are going through it. And it's hard, I say, 'How can you do…or how can you say that?' You know, but yet, I'm not …how can…how can

I say it…I went through the same thing and yet it continued for a while. And it was hard." (Lines 434-440)

Minga shared her difficult childhood which led to becoming a ward of the state along with her four siblings at a young age. She stated: "Well, I was raped, abused…I was chained up by my grandfather." (Lines 101-102) "I was five years old when I was taken away from my Mom." (Line 108) "I'm talking and looking and seeing, but…the whole inside is just damaged." (Lines 136-137) "I was abused…from babyhood to teenager until into my twenties." (Line 219) "You know, you say something, you're going to get beat, either by your spouse or by your family. You know, but they're just going to throw you like a dog, call you all kinds of names." (Lines 223-224) I have marks to prove where I was beat." (Line 230)

Dolores described her abuse as follows: "I grew up by myself. At the age of nine, I ran away from home because of my abuse with my mother." (Lines 55-56) Just she was abusing physically. You know, beating me up and I left from home at the age of nine like I said and I ran away. I was living under the creeks, stealing clothes from clothes lines and starving. I just left…" (Lines 58-60) "My mother never did love me. I couldn't even get close to her because she would slap me or grab me from my long hair. I used to have real long hair. Grab me from my hair and throw me against the wall. Or she would just lock me in a closet, wouldn't feed me for two or three days, wouldn't give me even a glass of water… (becomes tearful)… (pauses)…I went through hell with that bitch! I even had dreams about her. I used to see her. I used to see her beating me up. But when

I came out of prison that they told me she was dead…my mind started easing off, you know…and I would say, thank God, she's gone. She can't hurt me no more." (Lines 220-226) "All my life, I've been suffering…just like a dog…" (Line 234)

Christina shared her story: "I came from a very dysfunctional family." (Lines 150-152) "I guess I've survived a lot. I'm gonna need a tissue." (Line 252) (Crying) "I have suffered a lot in my life. I get emotional about it. I don't talk about it often. From the age of probably six, five, I think…I was molested through my teens. Typical, classic, child abuse survivor, and I didn't know that. I thought it was 'normal'…" (Lines 255-259)

Similarly, in describing her extended family Sylvia stated: "On my Dad's side of the family, you can say that it's a very dysfunctional side of the family." (Lines 358-359) "He [her father] feels real guilty for what he'd done to me as a child because he blamed me for everything, you know." (Lines 372-373) He'll come and bring me money or whatever I need, you know, because he doesn't want to question it because he knows what he did. My stepmother will call me the next day, 'Your dad was crying and apologizing.' And I know…" (Lines 393-396)

Alejandra also recalled the years of sexual abuse that she experienced at the hands of her maternal uncle. She recently went to see a counselor and this past trauma surfaced as she had managed to block it for years. *"Yo le confesé que (pause)…su hermano me había violado." (llorando) "Tal vez tendría…cinco años que yo recuerde y lo hizo (llorando) por bastante tiempo." "Nosotros vivíamos con ellos y el a veces tomaba y al*

siguiente día no iba a trabajar. Y mi mama se tenía que ir a trabajar y le comentaba que si iba con ella ayudarle o "X"...me decía no puedes ir..." "Me dejaba sola con el. En una ocasión le dije que yo le tenía miedo a el y no me contesto nada..." "...había decidido olvidar todo. De repente comencé a recordar todo." "Cuando yo ya estaba más grande, que yo ya empezaba a contestar...me ponía más agresiva...tendría ya quince años tal vez, ya no me tocaba..." (Lines 127-128) *"Prefería no haber comido pero no seguir viviendo con el. Pero ya falleció. Me hubiera gustado gritado, haberle acusado y esto no me deja en paz. (llorando) siempre me siento sucia. Cuando me baño me tallo por todos lados y..." (llorando)* (Lines 131-134) *"...yo prefería que me hiciera daño a mi porque tenía miedo. Tengo dos hermanas más, y tenía mucho miedo que les hiciera algo y yo trataba que no se les acercara* (Lines 139-140) Translation: "I confessed to her [her mother] that her brother had violated me." (Crying) (Line 109) "Yes, perhaps I was five years old as I can recall and it went on (crying) for a long time." (Lines 111-112) "We lived with them [an aunt and uncle] and he would sometimes drink and the following day he would not go to work. And my mother needed to go to work and I would ask her if I could go with her to help her and she would tell me I could not go." (Lines 115-117) "She would leave me alone with him. On one occasion I told her that I was fearful of him and she did not say anything." (119-120) "I had decided to forget everything. Suddenly, I started remembering everything." (Line 123) "When I was older and had begun to talk back…I was more aggressive…I must have been about fifteen, and he didn't touch me anymore (pause)…I remember that my mother commented that one

time they had complained to Mama because he had shown his "parts" to the neighbor's girls. I could not believe how she was not capable of confronting him…she could not do it…I would have preferred to have not eaten than to continue living with him. But he already died. I would have loved to have screamed and accused him and this does not leave me in peace. I always feel dirty. When I bathe I scrub myself all over and… (Lines 127-134) "I would have preferred that he harm me because I was very fearful…I have two more sisters and I was so afraid that he would do something to them and I would try to keep him from coming near them." (Lines 139-140)

At least three other women shared their stories regarding past traumas, but the ones above were the most severe cases I heard. These women have demonstrated great strength and resilience in surviving and coping with their past traumatic experiences and when they compare this to living with HIV, they often comment on how it is "just one more thing" in their life. This also contributes greatly to the impact it has had on their mental health and why depression appears to be common among these women. Although they have managed to survive and cope, they often block it out as a defense mechanism (as in the case of Alejandra) until it happens to re-surface and they have to re-experience their past pains in order to move on and begin to heal from these horrific traumas. These struggles are all interrelated and help to make meaning of how Mexican American women cope while living with HIV.

"Normalizing" Life with HIV

Another unexpected finding about how these women cope with HIV involves their desire to make their life with HIV as *normal* as possible. They stress that they want people to treat and view them as being *normal* despite their HIV status. This theme is significant in that at least eight participants mention wanting to be treated like they are *normal* or simply describe their life as *normal.*

Mary 1 stated: "I don't think I would have been able to get out of the house if it wasn't for the support group and family, it means a lot to me. I finally told them [family] and they have accepted it and they treat me *normal*. You know it is not like treating me with gloves or anything like that, everybody treats me the same. So sometimes I think I forget I am sick because I am healthy and thank God for that." (Lines: 108-113)

Sylvia describes coping with HIV: "I feel that has helped me a lot. I feel once, people can see what I can do… they can still let me live a *normal* life." (Lines: 93-94) She goes on to say that women with HIV can go on with their lives: "They can still do what they used to do. They just need to slow down…take care of their health. As long as you take your medications and do the proper things, you can live a lot longer. And support groups and other friends helping you out really helps a lot and women need to understand that there's no reason to be scared. There's people out there that help you, you just gotta ask for it." (Lines: 94-98)

While discussing how she disclosed her HIV status to her mother, Delilah reports: "You know… she was worried about me and how I was going to feel, what was going to

happen, what was going to happen to me. And she just wanted to make sure that I was going to be okay. That's the way she is. Mom wants to know that her daughter is okay. So, she just wanted to know if I was going to be fine. I told her, I was very honest, I told her, what you see is what you get. If you see me acting fine, acting *normal*, that's the way I am." (Lines: 126-131)

It also appears to be a factor when entering relationships and having to disclose to potential partners and running the risk of being judged as surfaced in the interview with Monica. It was clear that she felt looking *"normal"* was important to her. She states: "Because of my HIV. Regardless of other things that are okay and you know, I look *normal* and you know… how could that be? Or, rumors in the community with, you know… telling this person, "how could you be with her? Don't you know that…?" You know… all that stuff comes with it...because I've had to deal with that in…in, different relationships." (Lines: 416-420)

Becky sums it up by saying: "You know, I… these are people who will try to bring me up and telling me you know…everything is fine. It's just like nothing is wrong with me, I know something is wrong with me, but you know… it's like they don't… not to forget but just to live, day by day. You know… just to, *normalize* it... yes as *normal* as possible, as *normal* as possible. (Lines: 252-257)

Blanca *"...me sentia como yo era normal. Soy normal pero, no, no estoy normal, yo se que no estoy normal. Se que tengo esa enfermedad, y nadie puede vivir con esa enfermedad tantos años y el grupo me ayudo mucho a fortalecer me y seguir viviendo*

con esta enfermedad." Translation: I felt as though I was *normal*. I am *normal*, but, no, no I am not *normal*, I know I am not *normal*. I know that I have this disease and no one can live with this disease for so many years… and the group has helped me so that I can go on living with this disease. (Lines: 72-75)

Elisa states: "Most of the time I try not to think about it. I just live my life, but I've been very fortunate, and my kids are healthy, so that's what keeps me and my husband going, and we try to give them a life that is as *normal* as possible. So I think that I've had a good life. God has been good to me. He really has." (Lines: 29-32)

Dora describes living a normal life by saying: "Pos en un principio fue bien difícil, pero ahora a tratado de sobre llevarlo. *Y creo que vivo una vida normal. Porque, gracias a Dios, pos hasta ahorita no he caído al hospital ni he tenido alguna enfermedad que me mortifique y me haga saber que tengo VIH."* Translation: Well, initially it was very difficult but now I try to take it in stride. I believe that I live a *normal* life. Because, thank God, well, up to now I have not had to be hospitalized nor have I had a secondary infection that has concerned me and that has disclosed that I have HIV. (Lines: 20-23)

"Un Dia a La Vez"

At least four women commented that they have lived "One day at a time" translated into Spanish as *"un dia a la vez."* There is a popular Spanish song that is entitled *"Un dia a La vez"* which is commonly sung at burial sites or memorial services. It is intended to reflect on how the deceased lived his/her life "one day at a time" while

confronting and coping with everyday struggles. Different populations and/or individuals possess their own unique way of making meaning of a disease like HIV/AIDS. The broader influences that help form their meaning can include religious beliefs, gender roles, cultural factors, class, and socioeconomic factors, such as poverty, racism, and sexism. This is to say that Mexican American women make sense of living with HIV within the broader context of their lives. It also supports the notion that despite the many challenges they may be facing, their level of resiliency acts as a source of strength to help them cope.

Clearly, HIV positive women face a multitude of challenges. Regardless of their past experiences, these women are often remarkably resilient. As some will tell you they have been to hell and back, and life, even with HIV is better now (Goggin & Rabkin, 1997). Mary stated: "I always say… HIV is the best thing that happened to me because it made me a better person. It made me trust God more and made me appreciate life more." (Lines 353-358) Given the enormity of the challenge, the family facing HIV disease must adapt to continual change and transition over the course of the illness and treatment. The resources of the family will be severely taxed, and these stresses may be particularly overwhelming for low-income, minority families who may already be struggling to meet basic, daily needs (O'Connor, 1997).

Comorbidities

Eleven study participants reported having comorbidities (dual or multiple diagnoses) in addition to their HIV diagnosis, ranging from Type II diabetes, pulmonary disease, hepatitis C, sleep apnea, hypertension, heart disease and mental illness. Mary 1, Christina, Delilah, Sylvia and Rebecca all have Type II diabetes. They all report to have had problems with controlling other diseases and some of them have stated that the symptoms of these conditions seem to have heightened as a result of their compromised immune system. Besides the diagnosis of major clinical depression, five women had a diagnosis of bi-polar and anxiety disorder, and one woman had schizophrenia and mild retardation. These co-conditions add present stress in their lives make it more challenging to cope with daily struggles and with HIV.

In the next chapter, I will review the findings presented in this chapter. I will conclude by discussing the limitations of the study, implications for social work practice and education, and recommendation for future research.

Chapter Six

Discussion and Implications

In the previous chapter, the findings of this qualitative research dissertation were introduced in great detail. This chapter will review and discuss those findings, including the unexpected findings, and discuss the limitations of this dissertation. It will conclude with implications for social work practice and education as well as recommendations for future research.

Discussion of the Findings

This researcher explored how Mexican American women living with HIV cope and make meaning of their diagnosis. The central research question asked of the participants was how they lived with HIV. The following sub-questions were asked to the fifteen participants of this qualitative study:

(1) Who are those people or systems that support you in living with HIV?

(2) What role has the *Mujeres* support group played in your life?

(3) What are the major factors that influence you in your daily living with HIV?

The findings were split into two primary categories, (a) Strengths/Resources that were identified as positive means of healthy coping and (b) Barriers/Stressors that were identified as struggles that added to the daily challenges of the participants' level of coping while living with HIV. And lastly, some unexpected findings warrant discussion.

Triangulation was utilized in collecting the data in this qualitative study. This included one, or in some cases, two in-depth interviews; participation observation of study participants while conducting presentations and participating in meetings, follow up member checks to verify data, and peer reviews.

The Role of Support Systems (Family, Friends, and *Mujeres* support group)

The findings suggest the more support the women receive the better they cope with HIV. One common theme for the participants to cope well with their HIV diagnosis was having support from immediate family members. Another major source of support was to have experienced the acceptance of others through such means as the support group members who could identify with the participants in their daily struggles. This validated that they were not alone and that they could continue to have hope in living a "*normal*" life. The notion of *normalcy* was important to the majority of the participants. It seemed to help fight off the negative impact that accompanies stigma and discrimination related to HIV.

Even though participation in the number of *Mujeres* support group sessions varied among the participants, it was clear that most had something positive to say about attending. In some cases, participants found comfort in gaining support from other women while living through the initial phase of their HIV diagnosis. Others found the group to serve the purpose of a "second family" as they received ongoing support and felt

free from judgment by receiving unconditional love and acceptance. It should be noted that at the time of the interviews, the support group had met for twelve years and at least four women had been involved since the beginning and spoke favorably about how the group had helped them cope. The average number of years attending *Mujeres* support group was 9.13 years, ranging from one participant that had been attending for less than three years to four participants who had attended on a regular basis for the last twelve years.

Participants seem to need a strong connection to their family of origin or to a "second family" through their connection with *Mujeres* support group. This might be viewed as a cultural factor unique to Latinos living with HIV because of their strong sense of familial ties. Family plays a very strong role for most Hispanics, with ties among an extended network of uncles, aunts, cousins, grandparents, and family friends (Sandoval-Cros, 2009). A major strength in Hispanic families is the significance placed on relationship within nuclear and extended family which is referred to as *familismo* (familism) (Santiago-Rivera et al., 2002; Weaver, 2005). The need for interpersonal connections may be universal to people of all ethnic groups. While others may seek solace in friends, and regard them as important as relatives, the need to have a group referred to as "familia" seemed especially important to the Mexican American women in this study.

Finally, the women's desire to be around for their children was identified as a motivating factor that gave the participants the hope and strength to keep living. Some of

whom made goals related to the milestones in the children's lives. One of the women who did not have any children of her own related a special relationship with a niece. She reported to have made a goal of living until her niece had her quinceañeara. She claimed to have reached this goal and then made a new goal of wanting to see her graduate from high school and when she lived to see this, then went on to make the goal of living until she finished college. She stated that this gave her the hope to "keep going."

Major Factors that Influence Daily Living with HIV

Perhaps the major factor that appeared to influence participants' daily lives was their strong faith and their motto of living "*One day at a time.*" A theme that characterizes many Hispanic families is the importance of spirituality and religion. Weaver (2005) explains:

> Spirituality has a fundamental shaping influence on the lives of many Latinos. Catholicism is a defining force of family and gender roles for Latino people…Latino Catholicism revolves around the concepts of life and death. This fatalistic belief system emphasizes that God will provide. There is a pervading sense that much of what happens is beyond an individual's person control. (p.147)

The role that religion/spirituality plays in participants' lives is significant and is evidenced by their various responses explaining how they live with HIV. All but one participant referenced faith in God as central to her coping with HIV. The mention of putting things "in God's hands" was also common to how participants make meaning of living with HIV.

While the role of religion is identified as a source of strength, there seems to be another major factor that affects their daily living, the issue of depression. It was striking to see how many of the participants battled with depression at one point in their lives and for some this is an ongoing issue.

As mentioned in Chapter 5, eleven study participants reported suffering some form of depression at some point after their diagnosis, nine reported to have undergone treatment with medications, and five admitted to having contemplated suicide. As previously noted, estimates reveal that 78% of HIV-infected individuals diagnosed as depressed had a history of depression prior to HIV infection diagnosis (O'Connor, 1997). Depression is more prevalent among women with HIV. HIV positive women are 20% more likely to be depressed than HIV positive men (Margolese, 2003). These study's findings are consistent with the studies among people living with HIV.

Unexpected Findings

A key finding of this study was the history of trauma found in the lives of the participants. At least ten of the fifteen participants reported some form of trauma. In some cases, participants experienced childhood trauma that included severe cases of child physical abuse, sexual abuse, and incest. Others revealed being victims of domestic violence. Several participants stated that if they had survived these traumas that HIV was "just one more thing" in their life they were forced to face as a challenge or struggle. The point can be argued that through their resilience they have found a way to bounce back

after being diagnosed with HIV and able to focus on their sources of strength. The women of the study showed their resilience in several ways. Some of the women who had been in bad relationships improved their living situation by going back to school, taking on a job, volunteering, getting more involved with family and children. Despite the traumas and other adverse experiences, they were able to rise above and thrive. Some women spoke about how the HIV diagnosis changed their perspective on life and how priorities had shifted allowing them to do things for themselves that improved the quality of their lives.

Saleebey states that trauma and abuse, illness and struggle may be injurious…they may also be sources of challenge and opportunity. He believes that every individual, group, family, and community has strengths. Trauma is not predictive; it may weaken or strengthen the individual. Saleebey goes on to say that resilience is not seen as a trait or static dimension. Instead, it…

> …is the continuing articulation of capacities and knowledge derived through the interplay of risks and protections in the world. The environment continually presents demands, stresses, challenges, and opportunities. These become fateful, given a complexity of other factors—genetic, neurobiological, familial, communal—for the development of strength, of resilience, or of diminution in capacity (Saleebey, 1996, pg. 299)

This concept can easily be applied to the study participants' level of coping despite the adversity that they have had to face in their lives, before and after their HIV diagnosis. Whereas the strengths perspective focuses on capabilities, assets, and positive attributes rather than problems and pathologies, resiliency emphasizes the use of the

strengths to cope with adversity and survive, despite difficulties (Kirst-Ashman, K., 2011); Gutheil & Congress, 2002).

The conceptual framework presented in Chapter 3 was useful in analyzing the data collected for this study. Strengths perspective and resiliency model are relevant when applied to the findings. The women's stories clearly reveal how they are resilient despite struggles and adverse conditions they have overcome and how they have been able to rise above the challenges and still survive. Their strengths have allowed them to seek the help they need from their families and other support systems. Their strengths further allow them to dream and aspire which is evidenced in their ability to set goals and succeed while pursuing academic and professional careers.

Although substance use is often found to be one of the risk factors related to HIV infection, this specific group of women reported no history of substance abuse. However, what did surface was the current and/or past use of substances by their husbands/partners. Six study participants reported their partners to have been IV drug users before learning of their HIV diagnosis. These findings can suggest further study in this area.

Limitations of the Study

The limitations of this study include small sample size (n = 15), and a potential for sample bias given that random sampling was not employed. However, this is common to qualitative research designs. The trade off was that the researcher could reach deeper into the personal lives of participants and was able to learn more about their

experiences from a first-hand prescriptive. Another limitation was the bias involved in the women's the prior relationship with the researcher and their self-selection into the group and the agency's services.

Including only Mexican American women living with HIV did not allow for comparison of other ethnic/minority groups, such as African American women. However, due to the paucity of research with this specific sub-population, it is important to examine culturally-specific patterns with Mexican American women living with HIV. Another limitation related to not having a comparison group is that the study did not include women who have not participated in a support group like that of *Mujeres Unidas Contra el SIDA.* Perhaps women that did not have the social support of a group would have had a different voice. Their struggles may have looked different than the women in this study. For example, this does not include women who did not self-select to participate in a support group.

Generalizability could also be viewed as a limitation since the study focused on a small sample of Mexican American women living with HIV from San Antonio or even of others in the San Antonio area. It could be argued that their experiences may not be the typical experiences of ALL Mexican American women living with HIV. Furthermore, regional differences may exist between Mexican American women living in South Texas vs. Mexican American women living in Southern California.

Implications for Social Work Practice & Education

While *women of color*--Black, Latina, Asian American, and Native American--constitute a large proportion of most social work caseloads, the unique needs of *women of color* are rarely presented in the social work literature (Gutierrez, 1990); therefore, this study's findings is a major contribution to social work.

It is crucial that social workers begin to listen to the voices of Mexican American women to better understand their lived experiences and how they make meaning of their unique challenges. It is not enough to have others try to understand behavior through assumptions and stereotypes. It is through these means that oppressed populations have been historically and mistakenly diagnosed as pathological and/or deviant without truly understanding the differences and honoring a culture's norms and traditions. Therefore**,** it is important for social workers to gain insight as to the cultural context of Mexican American women living with HIV and understand the ways that they cope and make meaning of their diagnosis.

There are not enough prevention or service programs based on culturally-relevant and peer-based models. Given the stigma of AIDS, the need is even greater in developing effective tools and strategies in reaching the Latino community. Greater emphasis needs to be placed on designing media campaigns that target the entire Latino family. By focusing on the Latino family, the long-felt stigma associated with the virus can begin to be eliminated. In addition, such models and strategies will do a great deal to engender a supportive family environment for Hispanics living with HIV, which

contributes greatly to the social support needed to adhere to HIV/AIDS treatment regimens (NCLR, 2006). Social workers can take the lead in developing and implementing effective, culturally and linguistically appropriate interventions for Mexican American women whose lives are impacted by HIV.

Moreover, it is important for social workers to develop and implement effective, culturally and linguistically appropriate interventions for Mexican American women whose lives are impacted by HIV. Social workers should be challenged to work and immerse themselves in the Latino community at large in helping to shape and enhance the positive image of the community's strengths and break down barriers such as stigma and discrimination that society can place on individuals living with HIV.

As the number of cases of HIV/AIDS increases, the need for counseling and other mental health services becomes apparent. It would therefore be practical for Schools of Social Work to include curriculum that addresses the needs of people with AIDS. Just as social workers are challenged to consider cultural diversity issues as they relate to child abuse, alcoholism, domestic violence and mental illness, the profession needs to take responsibility for addressing cultural influences in working with ethnic minorities who are living with HIV/AIDS (Rodríguez-Escobar, Pomeroy, Holleran & Neal, 2004).

When the AIDS epidemic first arose, social workers found themselves providing mostly emotional support to families and significant others, specifically in the area of death and dying. Now that HIV/AIDS is recognized as a more chronic and manageable disease, social workers are being challenged to expand their knowledge base and move

into the area of long-term counseling, as well as HIV/AIDS prevention. Culturally appropriate knowledge and skills are required (Rodríguez-Escobar et al., 2004).

Recommendations for Future Research

Research is desperately needed to help social workers and other mental health providers learn new ways to counsel Mexican American women living with HIV. This is particularly important for social workers and Schools of Social Work in the Southwest where large numbers of Mexican American women reside and are HIV positive. The potential is high for social workers in this region to encounter Mexican American women living with HIV due to the HIV prevalence rate found in this ethnic group, as well as the composition of a large Mexican American population in this particular region. The states with the largest Latino populations are California, New York, Texas and Florida (de la Garza and DeSipio, 2005).

The lack of research with this sub-population may result from Mexican Americans underutilization of mental health because these services lack linguistic and cultural relevance (Lopez, 2002). Therefore, research is needed in studying the few effective mental health services that exist in the Latino community, such as interventions and support groups specific to Mexican American women living with HIV, i.e. *Mujeres Unidas Contra el SIDA*. A case study approach may be in order to learn the specific tactics used by programs that effectively reach the sub-population studied in this dissertation and to examine them as best practices for duplication purposes. A collection of culturally and linguistically competent programs specific for Mexican American

women living with HIV will also shed light on how "home grown" interventions are initiated. This could be a mechanism used to adapting these approaches into evidence-based practices for hard-to-reach communities. Overall, research is needed to develop best practice interventions that directly impact the lives of *women of color*.

Inquiries related to identifying effective strategies for helping women living with HIV/AIDS address stressors such as social stigma, infidelity, religiosity, marital obligation, and other culturally related pressures would augment our understanding of social work practice with this population. In addition, such research could identify more effective coping strategies for Mexican American women living with HIV/AIDS.

Other findings drawn from this study suggest the need for a closer examination of the intersection between Mexican American women living with HIV and past traumatic experiences. Past trauma can be defined as partner violence, incest, child physical and/or child sexual abuse, rape, assault, and other traumatic incidents experienced in their lives. Potential research questions include: "Do these past traumas make Mexican American women more resilient and able to cope better while living with HIV?" "Does a history of abuse place Mexican American women at a higher risk for HIV?" "Are Mexican American women who have experienced some form of past trauma more resilient and better able to cope when confronted with an HIV diagnosis?" This is an area that warrants further research.

Although, this study focused on Mexican American women, future research is needed to compare this sub-population to women living with HIV who are Mexican-born.

This dissertation included four women born in Mexico who have lived in the United States for several years and who have children who are American citizens. There may be some cultural differences found in examining how these two groups cope with their lived experiences. A potential research question could be: "Do Mexican American women living with HIV have the same coping skills as Mexican-born women?" An additional study could include a cohort of women living with HIV who reside in Mexico and compare them to a cohort of Mexican-born women living with HIV who reside in the United States.

Additional research is needed in studying the role that religion plays in the lives of Mexican American women living with HIV. As suggested in the findings, many of the participants revealed that they left things up to "God's will." Among the unexpected findings, the theme of viewing their situation from the perspective of *"un dia a la vez"* (one day at a time) also suggests that the belief that the course of their lives is not necessarily under their control which could be related to *fatalismo* (fatalism). The lyrics of the song that mentions this saying goes on to say that the only thing they ask is for God is to let them live their life one day at a time, which further refers to the theme of faith in God. In a qualitative study conducted by Berry (1999), findings suggest that Mexican American women accessing prenatal care frequently expressed feelings indicating that they saw illness as a punishment from God or as a purposeful, God-sent event. These individuals yielded complete control to God's will reflecting the view that they felt they had little control over their lives and must put their trust in God to keep

them safe. Descriptors included phrases like: ‘‘it’s best to put it in God’s hands’’ and ‘‘if it is God’s will, I will heal’’ (Berry, 1999). This discussion leads to the need for closely examining levels of acculturation among study participants. “Does the level of acculturation play a role in how Mexican American women cope with HIV?”

Lastly, although the majority of the study participants met the federal poverty level guidelines, poverty did not surface as a stressor. Further exploration on the theme of poverty could add insight on how women cope.

Conclusion

Understanding the coping strategies of Mexican American women living with HIV/AIDS provides social workers and others who serve them and their families a better understanding of their needs. This research provides a richer understanding of the lives of a group of Mexican American women living with HIV. Moreover, this research demands that social workers and other researchers examining coping skills address the issues of resiliency and strengths perspective in understanding the ways in which the life journey unfolds for Mexican American women living with HIV.

Social workers need to examine new paradigms, strategies, and interventions that will focus on the broad social, economic, and community factors that put Mexican American women and other women of color disproportionately at risk for HIV. These broader factors are the social determinants of health. Poverty, income and wealth

inequality, poor quality of life, racism, sexism, and low socioeconomic status are the major risk factors for ill health and health disparities.

The findings of this study further suggest the need for social workers to take a more active role in advocating for the need for more culturally competent practices, and policies while serving this sub-population.

Finally, these important findings focusing on Mexican American women living with HIV is a great contribution to the field of social work due to the paucity of research with this population. It provides insight and understanding regarding the dynamics specific to HIV positive Mexican American women. This research will help identify ways for social workers to adopt culturally and linguistically appropriate interventions (best practices) while working with Mexican American women living with HIV.

Appendix A: Information Sheet

Research Project Title:	Coping Strategies Among Mexican American Women Living with HIV
Researcher:	Yolanda Rodríguez-Escobar, LMSW Doctoral Candidate University of Texas at Austin School of Social Work 2224 Fresno San Antonio, Texas 78201 (210) 734-7840 or (210) 867-9427
Faculty Advisor:	Laura Lein, Ph.D, Professor, School of Social Work, University of Texas at Austin, 1925 San Jacinto, Austin Texas, 78712 (512) 471-9248
Participant Selection Criteria:	Mexican-American Females Age 18-65 HIV Positive Participated in at least one support group at *Mujeres Unidas Contra el SIDA*
Participant Requirements:	Agree and give consent to participate in an in-depth interview to be conducted in a place of comfort for the participant. Interviews will include a brief demographic questionnaire. Interviews will be conducted in English and/or Spanish according to participant's preference. Duration of interview will be no longer than two hours. Participants will be paid $25.00 for their time to complete the interview.
Study Site Requirements:	Assist in the identification of clients meeting selection criteria, and assist in contacting potential participants to schedule interviews.

Thank you for your help conducting this research study. Questions or concerns about the project may be directed at any time to Yolanda Rodríguez-Escobar or Dr. Laura Lein at the telephone numbers listed above. Results of the study will be shared with the study site/organization upon completion of the study.

Appendix B: Recruitment Flier

"Coping Strategies Among Mexican American Women Living With HIV"

Interviews can be conducted in English or Spanish

Interviews will take about two hours

Receive $25.00 for your time

Researcher:

Yolanda Rodríguez-Escobar, LMSW
Doctoral Candidate
at the University of Texas at Austin

Are You a Mexican American Woman living with HIV?

Are you between the ages of 18 and 65?

Have you attended at least one support group at Mujeres?

Please contact Yolanda Rodríguez-Escobar for more information on how to participate
210-738-3393
210-867-9427

YOU ARE INVITED TO PARTICIPATE IN A RESEARCH STUDY

This is being done in an effort to learn more about the experiences of Mexican American Women Living with HIV. Participation is voluntary.

Appendix C: Consent Form (English)

CONSENT FORM

COPING STRATEGIES AMONG MEXICAN AMERICAN WOMEN LIVING WITH HIV

You are invited to participate in a study of Mexican American women who are living with HIV. My name is Yolanda Rodríguez-Escobar and I am a Doctoral student at the University of Texas at Austin, School of Social Work. This study is my dissertation research project. My study will explore how Mexican American women living with HIV cope with their diagnosis. You are being asked to participate in the study because you are or have been a member of a support group (*Mujeres Unidas Contra el SIDA*) whose mission is to serve Latinas whose lives are impacted by HIV/AIDS. I hope to learn the different ways Mexican American women cope with the many challenges related to this health condition and would like to see if cultural factors play a role in the way that you deal with HIV in your lives. If you decide to participate in this research, you will be one of approximately 15-20 women in the study.

If you decide to participate I will schedule an audio-taped interview with you to take place at your home or at an agreed upon location that will offer you the privacy and comfort needed to answer the questions I will be asking. The interview will take approximately two to three hours depending on how much information you decide to share. I will ask questions about how you are affected by your HIV diagnosis and about the issues related to coping with this illness. I will also ask you about your cultural background, your ideas about how culture affects the way you look at how you handle life challenges. This will be the only time your participation is requested.

The possible benefits of participating in the study include the opportunity to reflect on how you are managing your life with HIV and to think about ways that have helped you to cope. It may help you to recognize cultural strengths and validate the positive ways you look at different life experiences. This could potentially help you to deal with future life challenges you may face. Social Work educators could potentially use the information gathered from this study in planning the most effective ways to teach about how to offer assistance to individuals living with HIV in a culturally relevant way. There is a potential benefit to future social workers and clients who may find

themselves in similar situations as there are few studies that are specific to Latinas and HIV and even fewer that specifically target Mexican American women living with HIV.

The potential risks of participating may include the fact that these topic areas might prove to be difficult to think about or may cause stress in thinking about them. You may find some topics difficult or painful to talk about. If topics become too uncomfortable for you, we can stop the interview at any point. If this happens, you can take a break until you feel you can continue the interview. You may also choose not to answer certain questions if they are too difficult. None of the information you provide will be disclosed to anyone. All information discussed in the interview will be kept confidential. All cassette tapes will be kept in a locked file cabinet in my home during the study. When the study is completed, all cassette tapes, documents, and notes will be destroyed. No one will be able to link your responses to your name and you may choose a different name to protect your confidentiality. Your decision whether or not to participate will not effect your future relations with The University of Texas at Austin or *Mujeres Unidas Contra el SIDA*.

If you have any questions about the study, please ask me. If you have any questions later, you may call me at (210) 734-7849 or you may call my supervisor, Professor Laura Lein, Ph.D. at (512) 471-9248. If you have any questions or concerns about your treatment as a research participant in this study, call Lisa Leiden, Ph.D., Director of the University of Texas at Austin Institutional Review Board for the Protection of Human Research Participants at (512) 471-8871.

You are making a decision whether or not to participate. Your signature below shows that you have read the information provided above and have decided to participate in the study. If you later decide that you do not want to participate in the study, simply tell me. You may discontinue your participation in this study at any time. You will be given a copy of this consent form for your records.

_____

Printed Name of Participant

_____ _____

Signature of Participant Date

_____ _____

Signature of Participant Date

Appendix D: Consent Form (Spanish)
Consentimiento para participar en una Investigación

Usted ha sido elegido para participar en una investigación de Mujeres Mexico Americanas que estan vivendo con el VIH. Mi nombre es Yolanda Rodríguez-Escobar y soy estudiante en la Universidad de Texas en Austin, La Escuela de Trabajo Social. Este estudio es parte de mi proyecto de investigación y uno de los requisitos para recibir mi doctorado. Mi estudio se enfoca en como Mujeres Mexico Americanas viven su vida con el VIH. Este formulario le proporciona información acerca de la investigación. La razon porque ha sido elegido para participar en esta investigación es porque es miembra de un grupo de apoyo (*Mujeres Unidas Contra el SIDA)* que se dedica a servir Latinas que estan viviendo con el VIH/SIDA. Espero aprender las diferentes maneras en que las mujeres Mexico Americans hacen frente con sus retos tocante esta condición que le afecta a su salud y tambien quisiera ver si factores culturales tienen influencia sobre la manera en que viven su vida con el VIH. Si decide participar, sera una de aproximadamente 15-20 mujeres en esta investigación.

Si decide participar, sera fijado una cita para una intrivsta grabada en su hogar o en un lugar privado en donde se puede sentir cómoda en contestar las preguntas que le voy hacer. La intrivista se tomara aproximadamente dos o tres horas y depende en cuanta información vaya compartir conmigo. Le voy hacer preguntas sobre los afectos de su diagnoses de VIH y como es que hace frente con esta enfermedad. Tambien le voy a preguntar sobre su herencia cultural, sus ideas de como afecta la cultura en como enfrenta los retos que vienen con viver con VIH. Esta es la unica vez que le pedimos su participación.

Los beneficios que puedan suceder si usted decide participar en esta investigación inclue la oportunidad de reflexión en como usted está manejando su vida con el VIH y pensar de manaeras que le han ayudado en viver saludable. Ademas, le puede ayudar en reconocer las fuerzas cultural y dar validez a las maneras positivas en ver su perspectiva en tener la experiencia personal de vivir con el VIH. Estos resultados tienen la potencial de ayudare a los profesores en la área de el trabajo social para usar la información de este estudio en enseñiar a otros estudiantes a conocer como trabajar y ofrecer servicios a las personas afectadas con el VIH usando una manera que toma en cuenta la cultura de el cliente. Otro beneficio es directamente para trabajadores sociales y clientes que se

encunetran el la misma situación porque hay muy pocos estudios que son específicamente tratando de estudiar a mujeres Latinas con el VIH y hay menos estudios que son específicamente enfocandose a mujeres Mexico Americanas.

La potencial de los riesgos en partcipar en esta investigación pueden ser que en hablar de la tema sobre su enfermedad le podrar causar estrés. Es posible que se encuentre con dificultad en hablar de ciertas temas y que pueden causar daño o lastimar. Si algún momento no quisiera continuar y interrumpir su participación en esta investigación por alguna razón, usted tiene este derecho. Tambien tiene el derecho de no contestar ciertas preguntas que encuentra muy difícil para contestar. Todos los documentos de la investigación son privados y se protegerán la confidencialidad de esos documentos hasta el punto permitido por la ley. Todas las cintas grabadas van estar seguradas en mi casa en un cabinete cerrado con llave durante el estudio y destruidos juntos con las notas y los de mas documentos tan pronto que se termine esta investigación. Nadie podrar identificar sus repuestas con su nombre y tendra la opción de escojer un nombre falso para protejer su confidencialidad. Su participación en esta investigación es totalmente voluntaria. Su decision para participar o no participar en esta investigación no le afectara su relación con la Universidad de Texas en Austin o con *Mujeres Unidas Contra el SIDA.*

Si usted tiene algunas preguntas acerca de esta investigación, favor de preguntarme. Si usted tendra algunas preguntas despues de terminar con este estudio, se puede comincar conmigo y llamar a (210) 734-7840 o con mi Profesora, Laura Lein, Ph.D. y llamar a (512) 471-9248. Si usted tiene alguna queja, preocupación o pregunta acerca de la investigación, favor de hablar con Lisa Leiden, Ph.D., la Directora en la Universidad de Texas en Austin del Institutional Review Board for the Protection of Human Subjects, o a la Oficina de Investigaciones Conformidad y Soporte a (512) 471-8871.

Firmas:

Como representante de esta investigación, yo he explicado el propósito, los procedimientos, los beneficios y los riesgos que pueden estar involucrados en esta investigación:

Usted ha sido informada acerca del propósito, procedimiento, posibles beneficios y riesgos de esta investigación y usted ha recibido una copia de esta forma. A usted se le ha dado la oportunidad de

hacer preguntas antes de firmar y se le ha informado que puede hacer preguntas en cualquier momento. Voluntariamente usted acepta participar en esta investigación. Al firmar esta forma, usted no esta evadiendo ninguno de sus derechos legales.

_____

Nombre de la persona dando su consentimiento

_____ _____

Firma de la Persona Fecha

_____ _____

Firma de la Investigadora Fecha

Appendix E: Demographic Questionnaire

Central Question: How do Mexican American women living with HIV cope and make meaning of their diagnosis?

Yolanda Rodriguez-Escobar, LMSW
Doctoral Candidate at the University of Texas at Austin

Date of Interview _____

Fictitious Name of Interviewee _____

Site _____

Coping Strategies Among Mexican-American Living with HIV

I'm going to begin by asking you some general questions about yourself.

DEMOGRAPHIC INFORMATION

1. How old were you on your last birthday? _____
2. Where were you born? _____
3. Have you always lived in the U.S.? ____ Yes ____ No (If no, go to # 4 or skip if yes).
4. How old were you when you came to the U.S.? _____
5. What was the first language you spoke? _____
6. What language(s) do you currently speak at home? _____
7. How long have you been involved with *Mujeres?* _____
8. What do you consider your race/ethnicity to be?
_____ Mexican
_____ Mexican-American
_____ Latina, not of Mexican descent
_____ Other

9. How many years of school have you completed?

(Circle the number of years)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18

_____ 12 years, with high school diploma
_____ GED
_____ High school plus other (not college) training
If yes, identify the training _____
_____ some college
_____ Have college degree Type _____
_____ Some graduate work
_____ Graduate degree Type _____

10. What is your current marital status?
_____ Married
_____ Single, never married
_____ Single, divorced
_____ Separated
_____ Common-law marriage
_____ Widowed

11. What is your current relationship with the person who you believe infected you with HIV?
_____ Married
_____ Divorced
_____ Common-law marriage
_____ Cohabitating (living together)
_____ Dating (romantically involved, not cohabitating)
_____ Person is deceased
_____ No contact
_____ Don't know who it was
_____ Other: describe _____

12. Who are your closest family members, if any? (not names, but descriptions of relatives) **Circle those that apply:** uncle, aunt, grandmother, mother, father, brother, sister, cousin, nephew, other relative, closest non-relative, pastor or preacher, other: _____

13. Do you have a job for pay?
_____ No
_____ Yes If yes, what type of work do you do? _____

How many hours a week? _____

14. What is your yearly family income now? _____
    _____ under $5,000
    _____ $5,000 - $9,999
    _____ $10,000 - $14,999
    _____ $15,000 – $19,999
    _____ $20,000 - $24,999
    _____ $25,000 – $29,999
    _____ $30,000 or above
    _____ Don't know
    _____ Declined to answer

15. How many children do you have (total, whether in they live with you or not)? _____How many are living with you? _____
    Have you told your children about your HIV status? _____ No _____ Yes If Yes, please tell me about their reaction to learning this. _____

    _____

16. Are you currently on welfare, food stamps, Medicaid, veterans benefits, other?
    ____ No ____ Yes If yes, which ones? _____

17. Do you have any physical disabilities (some problem that makes it hard for you to get around easily or do things for yourself)?
    _____ No
    _____ Yes
    If yes, what is it? _____

18. Do you have health insurance?
    _____ No
    _____ Yes

19. How do you pay for your HIV medications? _____

    _____

20. Are there other medications that you take other than for HIV?
    _____No _____Yes
    If yes, how do you pay for those? _____

    _____

21. Do you receive SSI or Social Security Disability? _____ No _____ Yes
If so, how long have you been receiving this benefit? _____

Appendix F: Probes

What made it possible for you to come to *Mujeres*?

What led to your decision to come to the support group at *Mujeres?*

How did you find out about the group/organization?

What was it like when you came for the first time to *Mujeres* and when you attended the first support group session?

Describe your most recent involvement with *Mujeres Unidas*. (Prompts: Has the experience been a positive one, has it been helpful; have the people in the support group/agency treated you in the way that you were expecting to be treated?

Would you please share how long you've been involved with the support group at *Mujeres?*

What do you like most about *Mujeres* and the support group*?* (prompts: safety, rules about confidentiality, feeling of family, structure, support, someone to talk to, family night, group for children, going to conferences, presenting for community, going to Health Fairs, volunteering, attending training and learning about HIV, etc.)

What do you dislike about *Mujeres*? prompts: (feel like my HIV status will be disclosed)

How well do you think the support group is meeting your needs?

What else could be done to help meet your needs or the needs of other women with HIV?

Now we will talk about your perceptions and the way you think about certain things related to your HIV status.

What does HIV mean to you? Please use your own words to describe this?

What does HIV mean to your family?

What is your biggest fear about being HIV positive?

Do you have fears about dying? If so, please share what those fears are.

Knowing what you know now about HIV, do you ever think you could have done something different in your life? If so, please share your thoughts.

What does coming to the support group at *Mujeres* mean to you (prompts: do you feel good about the decision, do you feel ashamed for coming here, do you think it was the best decision, are you unsure if you want to continue, do you think it means you are a strong woman or a weak woman, does it mean that you really care about yourself and/or your children, does it mean that you don't have enough friends or family to help you, etc.)?

Do you ever feel like you should hang around more with your husband/boyfriend/man OR spend more time with other women (prompts: do you think you should hang around more with other women or with your man; some women have said that they feel torn between supporting their man or supporting other women; some women have said they feel like they are betraying either their man or their women friends)?
Please share your thoughts.

Have you ever felt pressured to leave your husband/boyfriend/man because of something you have shared about him in group?

If yes, where does that pressure come from (family, friends, boss, children, friends, women from your support group at the *Mujeres*)?

Is it considered wrong (by you or your family or friends) to stay with the man/woman who infected you with HIV? Please share your thoughts about your response to this question.

How much of a part does HIV play in the decisions you make about your relationship(s) For example, do you think it is okay to date once you find out that you have HIV?

IS HIV the primary stressor in your life? If not, what is?

How do you feel about couples counseling? (prompts: is this a service that you think would be helpful to offer?

What advice would you give to another woman who is in your situation?

If another woman told you about her own HIV status without knowing that you too were HIV positive, what would be the first thing you would tell her? What kinds of things would you think she needed to know? Would you share your own status?

Now we will talk about things related to educating people about this issue of HIV/AIDS.

What type of information or sources of information do you trust or believe (prompts: your friends, TV, things you read, your family, *Mujeres*, or other)?

Are there support services that provide something like welfare resources (food, money, childcare, etc.) by your neighbors, friends, relatives, or church group? If yes, what do you call them (how does your family refer to them?) and would you please describe them.

Do you remember how you found out about them?
Please share how you found out. (prompts: always been a part of what our family does; through my church/pastor/priest; through a friend; etc.)

Do you use these first before contacting a "formal" agency?

Do you belong to a church or community organization? If yes, what type of organization? Please provide the name of the place you go to.

If you said yes to church, do you attend their functions? If yes, how often?

How important is religion/spirituality in your life?

How would you define religion/spirituality in your own words?

Do you go to/talk with your minister/priest/preacher/ or other spiritual guide about your HIV? If yes, how often? Do you talk to this person about the issues related to your HIV status?

Do you see your church as separate from other informal helping places (such as friends, family, community supports)? Why or why not?

Do you think mainstream services (like clinics or agencies serving women) would be better if they considered a person's religious practices or beliefs in their dealings with people? Why or why not?

Do you think women in your culture are closer than women in other cultures?
Why or why not?

How would you suggest women be told about the HIV/AIDS and other STDs (TV, radio, fliers in your neighborhood, church people talking about them)?

What do you think society's/government's responsibility is toward you and other women living with HIV?

Did or do you feel isolated, shameful, embarrassed, concerned about the negative responses of others towards your diagnosis and, as a result, do you choose to talk to anyone about the HIV?

How many people have you told about your HIV? Are there people you would like to be able to talk to about the problems you have regarding your diagnosis, but are too worried about their reaction or what they might say? If yes, who, and what are you worried about?

What do you think should be done to help stop people from placing judgment on those who are living with HIV?

What do you think should be done to work with family members and friends to educate them about HIV?

Support information

Who do you count on to listen (or support) you when you really need it? (prompts for all questions: is that person related to you, and if so how?)

Who is the person or people in your life you know you can count on when you are in a crisis?

Who is the person in your life who lets you feel totally okay about yourself?

Who is the person who you believe really appreciates you as a person?

Questions about the future

What are your dreams for the future? (If you could do anything you wanted, what would that be?)

What do you do to have fun?

How do you deal with stress [what is stressful?] (prompts: laugh a lot, talk to others, watch TV, take a walk, attend retreats, go to church, watch movies, play games, play cards, clean, listen to music, don't deal with it, just hold it in, sometimes take it out on others)?

Have you ever thought about getting together with other women, renting or buying a house together, and helping each other with child care, transportation, etc.? (Explore: why, why not? Can you see advantages and disadvantages with this kind of arrangement? Would you ever consider doing this if there was a structure in place?)

Is there anything else that you would like for other people to know about your experience with HIV that has not been discussed? If so, please feel free to share your thoughts.

Appendix G: Glossary
Glossary of Terms

Women of color – refers to women that are members of different racial/ethnic groups to include African Americans, Latinos, Native Americans, Asian Pacific Islanders.

Men of color – refers to men that are members of different racial/ethnic groups to include African Americans, Latinos, Native Americans, and Asian Pacific Islanders.

Communities of color – refers to communities that are comprised of members of different racial/ethnic groups to include African Americans, Latinos, Native Americans, Asian Pacific Islanders that share similar struggles in fighting disparities, with the AIDS pandemic being one.

People of color – are members from communities of color described above.

PLWHA - is the acronym that refers to Persons living with HIV/AIDS

MSM - is the acronym and risk category that refers to Men who have Sex with Men

CDC - is the acronym that refers to the Centers for Disease Control and Prevention

HRSA - is the acronym that refers to the Health Resources and Services Administration

NIH - is the acronym that refers to the National Institutes of Health

NASTAD - is the acronym that refers to the National Alliance of State and Territorial AIDS Directors

NIAID - is the acronym that refers to the National Institute of Allergies and Infectious Diseases

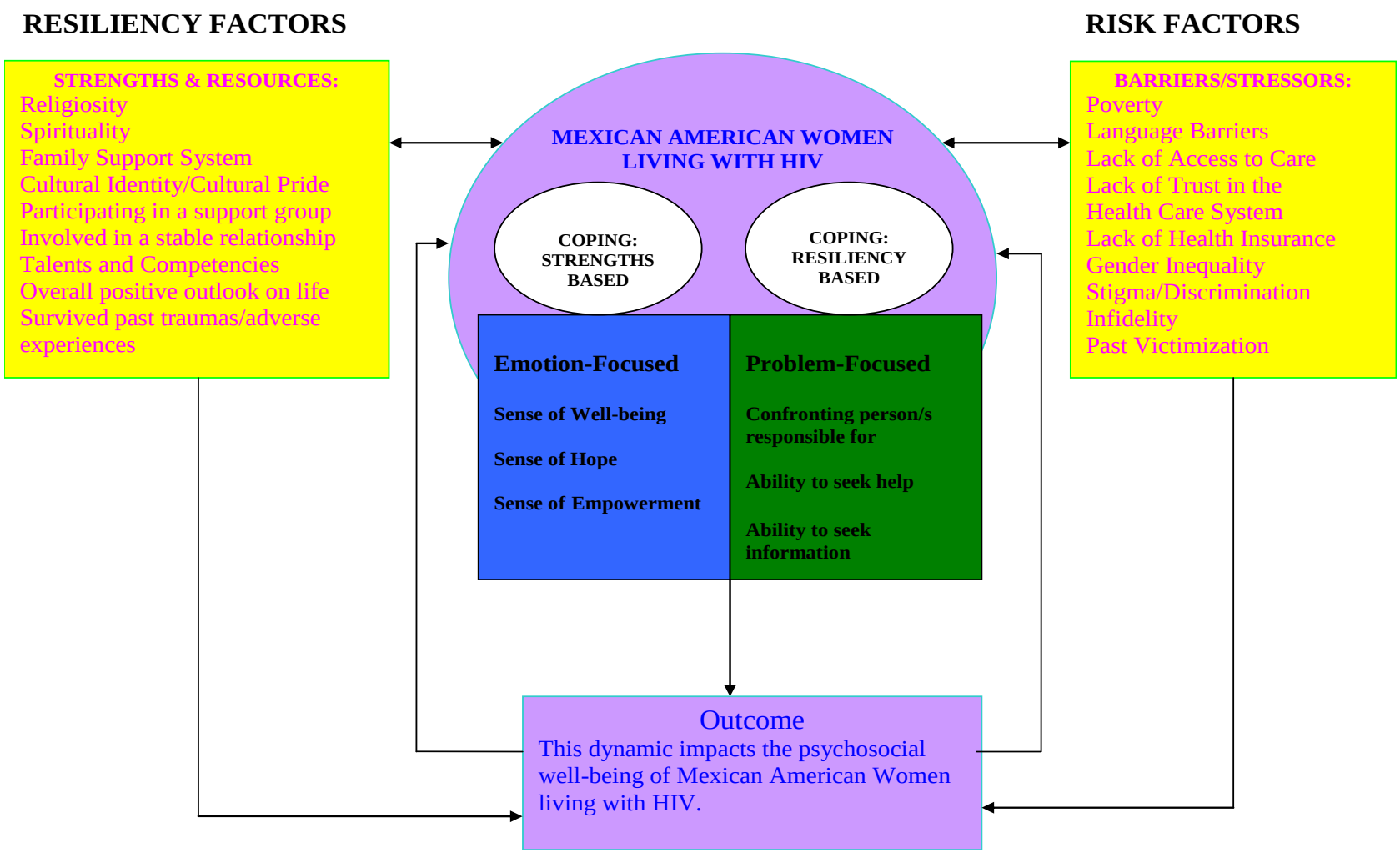
NMAC - is the acronym that refers to the National Minority AIDS Council

OMH – is the acronym that refers to the Office of Minority Health

MAI - is the acronym that refers to the Minority AIDS Initiative that was initiated by the Congressional Black Caucus to provide monies for capacity building to communities of color

ACT UP - is the acronym that refers to the AIDS Coalition to Unleash Power

Strengths Perspective/Resiliency Model



References

Abraído-Lanza, A. F., Viladrich, A., Floréz, K. R., Céspedes, A., Aguirre, A. N., & De La Cruz, A. (2007). Fatalismo reconsidered: A cautionary note for health-related research and practice with Latino populations. *Ethnicity & Disease, 17,* 153-158.

Abrams, L. (2002). Rethinking girls at-risk: Gender, race, and class intersections and adolescent development. *Journal of Human Behavior in the Social Environment, 6*(2), 49-66.

ACT UP. (1993). *U. S. immigration ban.* Retrieved from http://www.actupny.org/actions/immigration.html

ACT UP. (2003). *Capsule history: 1987, 2003.* Retrieved from http://www.actupny.org/documents/cron-87.html

Aguayo J., Brown E. R., Rodríguez, M.A., & Margolis, L. (2003). *Important health care issues for California Latinos: Health insurance and health Status. Health policy fact sheet 2003.*

Amaro, H. (1988). Considerations for prevention of HIV infection among Hispanic women. *Psychology of Women Quarterly, 12*(4), 429-443.

amfAR AIDS Research News and Media. (2008). *Results of a national survey of public perceptions of women living with HIV/AIDS.* Retrieved from http://www.amfar.org/cgi-bin/iowa/news/record.html

amfAR AIDS Research News and Media. (2006). *Twenty-five years of AIDS-World.* Retrieved from http://www.amfar.org/cgi-bin/iowa/news/record.html

Angel, R. J., Lein, L., & Henric, J. (2006). *Poor families in America's health care crisis.* New York: Cambridge University Press.

Aquino, M. P. (1993). *Our cry for life. Feminist theology from Latin American.* (Trans. D. Livingstone). New York, NY: Maryknoll.

Aranda, M. P., Castaneda, P. J., Lee, E., & Sobel. (2001). Stress, social support, and coping as predictors of depressive symptoms: Gender differences among Mexican Americans. *Social Work*

Arches, J. L. (1997). Connecting to communities: Transformational leadership from Africentric and feminist perspectives. *Journal of Sociology & Social Welfare, 24*(4), 113-124.

Arretiere, J. (2006). To AID together. *Colors, Spring (Primavera).*

Asbury, J. E. (1987). *African-American women in violent relationships: An exploration of cultural differences*. United States: Lexington Books.

Atkinson, P. & Hammersley, M. (1994). Ethnography and participant observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp.248-261). Thousand Oaks: Sage Publications.

Atkinson, P. & Hammersley, M. (1998). Ethnography and participant observation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp.110-136). Thousand Oaks: Sage Publications.

Baldwin, A. L., Baldwin, C. P., Kasser, T., Zax, M., Sameroff, A., & Seifer, R. (1993).

Contextual risk and resiliency during late adolescence. *Development and Psychopathology, 5,* 741-761.

Berry, A. (1999). Mexican American womens' expressions of the meaning of culturally congruent prenatal care. *Journal of Transcultural Nursing, 10*(3), 203–209.

Berry, A. (2003). Conceptual approaches to acculturation from acculturation. In Chun, Balls, Organista, & Marin (Eds.), *Advances in theory, measurement, and applied research.*

Bialer, P. A., Bluestine, S., & Richards, J. J. (1997). Treating HIV in dual diagnosis patients. In O'Conner, M. (Ed.), *Treating the psychological consequences of HIV.* San Francisco: Jossey-Bass Publishers.

Bozzette, S. A. et al. (1998). The care of HIV-infected adults in the United States, *New England Journal of Medicine, 339*(26).

Brody, H. (1992). Philosophic approaches. In B. F. Crabtree & W. L. Miller (Eds.), *Doing Qualitative Research* (pp. 31-44). Newbury Park, CA: Sage Publications.

Campbell, C. A. (1999). *Women, families, & HIV/AIDS.* New York: Cambridge Press.

Centers for Disease Control and Prevention. (1982). Current trend Acquired Immune Deficiency Syndrome (AIDS): Precaution for clinical and laboratory staffs. *Morbidity and Mortality Weekly Report, 31*(43), 577-580.

Centers for Disease Control and Prevention. (2003). *A history of the CDC directly funded community-based HIV prevention program.* Distributed at Consultation on Community Based HIV Prevention Programs.

Centers for Disease Control and Prevention. (2004). Health disparities experienced by Hispanics --- United Sates. *Morbidity and Mortality Weekly Report, 53*(40), 935-937.

Centers for Disease Control and Prevention. (2004). *HIV/AIDS surveillance report 2003* (Vol. 15). Atlanta, GA: U. S. Department of Health and Human Services.

Centers for Disease Control and Prevention. (2005). HIV prevalence, unrecognized infection, and HIV testing among men who have sex with men --- five U.S. cities, June 2004 – April 2005. *Morbidity and Mortality Weekly Report, 54*(24), 597-601.

Centers for Disease Control and Prevention. (2006). Epidemiology of HIV/AIDS --- United States, 1981-2005. *Morbidity and Mortality Weekly Report, 55*(21), 589-592.

Centers for Disease Control and Prevention. (2008). Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006. *Morbidity and Mortality Weekly Report*, 57(36), 985–989.

Cervantes, R. C. & Castro, F. G. (1985). Stress, coping, and Mexican American mental health: A systematic review. *Hispanic Journal of Behavioral Sciences,* 7(1), 1-73.

Chazin, R., Kaplan, S., and Terio, S. (2000). *Resiliency enhancement: Putting the strengths perspective into social work practice* E. Norman, (Ed.). New York: Columbia University Press.

Chong, Nilda. (2002). *The Latino patient: A cultural guide for health care providers.*

Maine: Intercultural Press.

Collins, K. S. et al. (2002). *Diverse communities, common concerns: Assessing health care quality for minority Americans: Findings from the Commonwealth Fund 2001* (Health Care Quality Survey Publication #523). New York: Commonwealth Fund.

Cowger, C. D. (1994). Assessing client strengths: Clinical assessment for client empowerment. *Journal of the National Association of Social Workers,* 39, 262-268.

Crabtree, B. F. & Miller, W. L. (Eds.). (1992). *Doing qualitative research.* Newbury Park, CA: Sage Publications.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks: Sage Publications.

De la Garza, R. O. & DeSipio, L. (2005). Muted voices: Latinos and the 2000 elections. Lanham, MD: Rowman & Littlefield.

Department of Health and Human Services. (2004). *Fiscal year 2005 President's budget request for the National Library of Medicine. Women and minorities.* Retrieved from http://www.hhs.gov/budget/testify/b20040401u.html

Douglas, A. (1996). A rethinking of the effects of homelessness on children: Resiliency and competency. *Child Welfare, 75*(6), 741-751.

Echegaray, L. (2002). *The independent living resource center: Maria Sarti, Centro Latino*. Retrieved from http://www.sfcard.org/newsletters/news-03-01.pdf

Ell, K. & Castaneda, I. (1998). Health care seeking behavior. In S. Loue (Ed.), *Handbook of immigrant health* (pp.135-144). New York, NY: Plenum Press.

Estevez, L. A. (2005). Poor, oppressed, and prone to infection. Married, heterosexual, monogamous, Latino women living with Human Immunodeficiency Virus (HIV)/ Acquired Immune Deficiency Syndrome (AIDS) in San Antonio, Bexar County, Texas (Master's Thesis, Oblate School of Theology, San Antonio, Texas, 2005).

Faithfull, J. (1997). HIV-positive and AIDS-infected women: Challenges and difficulties of mothering. *American Journal of Orthopsychiatry, 67*, 144-151.

(2007). *Federal Register* (Vol. 72, No. 15, pp. 3147-3148).

Feldman, D. A. & Miller, J. W. (1998). *The AIDS crisis: A documentary history*. United States: Greenwood Publishing Group, Inc.

Felsman, J. K. (1984). Abandoned children: A reconsideration. *Children Today, 13*(3), 13-18.

Fenton, K. A. & Valdiserri, R. O. (2006). *Twenty-five years of HIV/AIDS – United States-1981-2006.* Retrieved from http://www.thebody.com

Folkman, S. & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219-239.

Foreyt, J. P. (2003). Cultural competence in the prevention and treatment of obesity: Latino Americans. *The Permanente Journal, 7*(2).

Fry, R. (2008). Latinos account for half of U.S. population growth since 2000. *The Pew Center*. Retrieved from http://www.pewhispanic.org

Gallego, S. M. (1998). Providing services to HIV-positive women. In D. M. Aronstein & B. J. Thompson (Eds.), *HIV and social work: A practitioner's guide* (pp. 431-442). Binghamton, NY: The Haworth Press, Inc.

Garcia, J. A. (1981). Political integration of Mexican immigrants: Explorations into the naturalization process. *International Migration Review.*

Gebo, K. A. (2004). *The Hopkins HIV report: HIV in patients over 50: An increasing problem.* Retrieved from http://www.hopkins-aids.edu/publications/report/nov04-2.html

Glicken, M. D. (2006). *Learning from resilient people: Lessons we can apply to counseling and psychotherapy*. Thousand Oaks, CA: Sage Publications.

Gochros, J. S. (1989). *When husbands come out of the closet.* New York: Harrington Park Press.

Goggin, K.J. & Rabkin, J.G. (1997). Treating HIV-positive women. In M. O'Connor (Ed.), *Treating the psychological consequences of HIV.* San Francisco: Jossey-Bass Publishers.

Goldstein, H. (1997). Victors or victims. In D. Saleebey (Ed.), *The strengths perspective in social work practice* (pp. 21-35). New York, NY: Longman Press.

Gottlieb, M. et al. (1981). Pneumocystis pneumonia-Los Angeles. *Morbidity and Mortality Weekly Report,*

Graham, J. (2004). *Fighting AIDS in our own back yard.* Retrieved from http://www.thebody.com

Greeley, A. (1995). Concerns about AIDS in minority communities. *FDA Consumer, 29,* 11-15.

Green, J.W. (1999). *Cultural awareness in the human services. A multi-ethnic approach.* Boston, MA: Allyn & Bacon.

Greene, R. R. (2002). *Resiliency: An integrated approach to practice, policy, and research.* Washington, DC: NASW Press.

Greene, R. R., Galambos, C., Lee Y. (2004). *Resilience theory. Journal of Human Behavior.* Retrieved from http://www.informaworld.com

Grothberg, E. H. (1995). Proceedings from Symposio Internacional Stress e Violencia: *The international resilience project: Research, application, and policy*. Libson, Portgual.

Gutheil, I. A. & Congress, E. (2002). Resiliency in older people: A paradigm for practice. In R. Greene (Ed.), *Resiliency: An integrated approach to practice, policy, and research* (pp. 40-52). Washington, DC: NASW Press.

Gutierrez, L. M. (1990). Working with women of color: An empowerment perspective. *Social Work, 28,* 149-153.

Hackl, K. L., Somlai, A. M., Kelly, J. A., & Kalichman, S. C. (1997). Women living with HIV/AIDS: The dual challenge of being a patient and caregiver. *Health & Social Work,* 22, 53-62.

Hadley, J. (2003). Sicker and poorer – The consequences of being uninsured: A review of the research on the relationship between health insurance, medical care use, health, work, and income. *Medical Care Research and Review, 60*(2), 3-75. doi: 10.1177/1077558703254101

Hall, H. I., Song, R., Rhodes, P., Prejean, J., An, Q., Karon, J., Brookmeyer, R, Janssen, R. S. (2008). Estimation of HIV incidence in the U.S. *JAMA, 300*(5), 500-529.

Hamburg, D. A. & Adams, J. E. (1967). A perspective on coping behavior: Seeking and utilizing information in major transitions. *Archives Psychiatry, 17,* 277-284.

Health Resources and Services Administration. (1998). Care ACTION: Providing HIV/AIDS care in a changing environment. *Women and HIV/AIDS,* 1-12.

Health Resources and Services Administration. (1999). Care ACTION: Providing HIV/AIDS care in a changing environment. *Hispanics Living with HIV Disease: Barriers to Care,* 1-8.

Healthy People 2020. (2010). *Disparities.* Retrieved from www.healthypeople.gov

Henry, D. L. (1999). Resilience in maltreated children: Implications for special needs adoption. *Child Welfare, 78*(5), 519-540.

Horwitz, A. V., McLaughlin, J., & White, H. R. (1998). How the negative and positive aspects of partner relationships affect the mental health of young married people. *Journal of Health and Social Behavior, 39*, 124-136.

Hovey, J. D. (2000). Acculturative stress, depression, and suicidal ideation in Mexican immigrants. *Cultural Diversity and Ethnic Minority Psychology, 6*(2): 134-151.

Hulewicz, J. M. (1994). AIDS knows no borders. *World AIDS, 35,* 6-10.

Ickovics, J. & Rodin, J. (1992). Women and AIDS in the United States: Epidemiology, natural history, and mediating mechanisms. *Health Psychology, 11,* 1-16.

Institute of Medicine. (2001). *Coverage matters: Insurance and health care*. Washington, DC: National Academies Press.

Jefferson, D. (2006). AIDS: 25 years later. How AIDS changed America. *Newsweek,* 27-67.

Jenkins, S. R. & Coons, H. L. (1996). Psychosocial stress and adaption processes for women coping with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care, 12*(4), 68-76.

Johnson, R. C. & Raphael, S. (2005). *The effects of male incarceration dynamics on AIDS infection rates among African-American women and men.* Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.150.5305&rep=rep1&type=pdf

Kaiser Family Foundation. (2001a). *Latinos and HIV/AIDS. Key facts.* Retrieved from http://www.kff.org/content/2001

Kaiser Family Foundation. (2001b). *Latinos' views of the HIV/AIDS epidemic at 20 years. Findings from a national survey.* Retrieved from http://www.kff.org/content/2001

Kaiser Family Foundation. (2002). *Kaiser daily HIV/AIDS report. Special report: Southern discomfort – Coping with HIV/AIDS in the South poses challenges.*

Retrieved from http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=15025

Kaiser Family Foundation. (2003). *AIDS drug assistance programs (ADAPs) fact sheet, April 2003: HIV/AIDS Bureau, Health Resources and Services Administration, AIDS epidemic and the Ryan White Care Act: Past progress, future challenges 2002-2003.* Retrieved from http://hab.hrsa.gov/tools/progressreport

Kaiser Family Foundation. (2004). *HIV/AIDS growing problem among Latinos, particularly women, National Latino AIDS Conference delegates say.* Retrieved from http://www.kff.org/content/2004

Kaiser Family Foundation. (2005). *Kaiser commission on key facts. Medicaid and the uninsured. The uninsured and their access to health care.* Retrieved from http://www.kff.org/uninsured/upload/The-Uninsured-and-Their-Access-to-Health-Care-Fact-Sheet-6.pdf

Kaiser Family Foundation. (2006). *Latinos and HIV/AIDS.* Retrieved from http://www.kff.org/content/2006

Kaiser Family Foundation. (2006). *Women and HIV/AIDS in the United States.* Retrieved from http://www.kff.org/content/2006

Kaiser Family Foundation. (2010). *Women and HIV/AIDS in the United States.* Retrieved from http://www.kff.org/content/2010

Kane, M.N. & Williams, M. (2002). Perceptions of south Florida Hispanic and Anglo

Catholics: From whom would they seek help? *Journal of Religion and Health, 39*(2), 107–121.

Kanuha, V. K. (2000). "Being native" versus "going native": Conducting social work research as an insider. *Social Work, 45*(5), 439-447.

Kirst-Ashman, K. K. (2011). *Human behavior in the macro social environment. An empowerment approach to understanding communities, organizations, and groups*. Belmont, CA: Brooks/Cole.

Kleinman, A. (1980). *Patients and healers in the context of culture.* Berkeley, CA: University of California Press.

Krouse, S. (2008). *HIV-positive women not likely to reveal condition.* Cox News Service.

Latino Commission on AIDS. (n.d.). A national perspective of the HIV/AIDS epidemic on Hispanics/Latinos in the U.S. *National Latino AIDS Awareness Day,* 17-22.

Lazarus, R. S. (1983). The costs and benefits of denial. In S. Breznitz (Ed.), *The denial of stress* (pp. 1-3). New York: International Universities Press.

Lazarus, R. S., Averill, J. R., & Opton, E. M. (1974). The psychology of coping: Issues of research and assessment. In G. V. Coelho, D. A. Hamburg, & J. E. Adams (Eds.), *Coping and adaptation* (pp. 249-315). New York, NY: Basic Books.

Lazarus, R. S. & Folkman, S. (1984a). Coping and adaptation. In W. D. Gentry (Ed.), *The handbook of behavioral medicine* (pp. 282-325). New York, NY: Guilford Press.

Lazarus, R. S. & Folkman, S. (1984b). *Stress, appraisal, and coping.* New York, NY:

Springer.

Lichtenstein, B. (2000). Secret encounters: Black men, bisexuality and AIDS in Alabama. *Medical Anthropology Quarterly,* 374-393.

Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry.* Newberry Park, CA: Sage.

Lofland, J. & Lofland, L. H. (1995). *Analyzing social settings (3rd ed.).* Belmont, CA: Wadsworth.

Lopez, S. R. (2002). Mental health care for Latinos: A research agenda to improve the accessibility and quality of mental health care for Latinos. *Psychiatric Services, 53,* 1569–1573.

Loue, S. (1999). *Gender, ethnicity, and health research.* New York, NY: Kluwer Academic/Plenum Publishers.

Lujan, J. & Campbell, H. (2006). The role of religion on the health practices of Mexicans. *Journal of Religion and Health, 45*(2).

Lum, D. (1999). *Culturally competent practice.* Pacific Grove, CA: Brooks/Cole.

Luthar, S. & Zigler, E. (1991). Vulnerability and resilience: A study of high risk adolescence. *Child Development,* 62(3), 600-616.

Lynch, M. (2000). Uneven ground: HIV in women of color. *Advance for Nurse Practitioners, 8*(1), 45-48.

Maldonado, M. (1998). The HIV/AIDS epidemic among Latinos in the United States. *National Minority AIDS Council (NMAC) Update,* 1-7.

Malgady, R.G. & Zayas, L.H. (2001). Cultural and linguistic considerations in

psychodiagnosis with Hispanics. The need for an empirically informed process model. *Social Work, 46,* 39-49.

Margolese, S. (2003). Women and depression. The Well Project. Retrieved from http://www.thewellproject.org

Marin, B. V. (2002). Collaborative HIV prevention research in minority communities program: A model for developing investigators of color. *Public Health Reports.*

Marin, B. V. (2003). HIV prevention in the Hispanic community: Sex, culture, and empowerment. *Journal of Transcultural Nursing*, *14*(3), 186-192.

Marte, C. (1998). Women. In R. A. Smith (Ed.), *Encyclopedia of AIDS: A social, political, cultural and scientific record of the HIV epidemic* (pp. 546-550). Chicago/London: Fitzroy Dearborn Publishers.

Masten, A. S., Best, K. M., & Garmezy, N. (1990). Resilience and development: Contributions from the study of children who overcome adversity. *Development and Psychopathology, 2,* 425-444.

Masten, A. S. & Garmezy, N. (1984). Risk, vulnerability, and protective factors in developmental psychopathology. In B. B. Lahey & A. E. Kazdin (Eds.), *Advances in clinical child psychology (Vol. 8)* (pp. 1-51). New York, NY: Plenum Press.

Mc Roy, R. (2002). *Research on social work practice.* Vol. 12: 440.

MedicineNet, Inc. (2010). *Definition of discordant couple.* Retrieved from http://www.medterms.com/script/main/art.asp?articlekey=38933

Milliman USA. (1993). *Insight. Healthcare*. Retrieved from

http://insight.milliman.com/healthcare.php

Mitchell, F. (2009). *Changing the conversation: Taking a social determinants of health approach to addressing HIV/AIDS among women of color.* White Paper prepared for Grant Makers in Health Meeting.

Monat, A. & Lazurus, R. S. (1991). *Stress and coping.* New York, NY: Columbia University Press.

Morales, L. S., Cunningham. W. E., Galvan, F. H., Andersen, R. M., Nakazono, T. T., & Shapiro, M. F. (2004). Sociodemographic differences in access to care among Hispanic patients who are HIV infected in the United States. *American Journal of Public Health*, 94(7), 1119-1121.

Moskovitz, S. (1983). *Love despite hate*. New York, NY: WW Norton.

Ms. Foundation for Women. (2006). *Women and AIDS fund*. Retrieved from http://www.msfoundation.org

Mujeres Case study, 1995

Multhoma County Health Department, Oregon Health Division. (2001). *Latino PLWH services, needs and barriers to care: Program design and evaluation services.*

Murphy, L. B. (1962). *The widening world of childhood.* New York, NY: Basic Books.

Murphy, L. B. (1974). Coping, vulnerability, and resilience in childhood. In G. V. Coelho, D. A. Hamburg, & J. E. Adams (Eds.), *Coping and Adaptation* (pp. 69-100). New York, NY: Basic Books.

National Alliance of State and Territorial AIDS Directors. (2002). *Addressing*

HIV/AIDS: Latino perspectives & policy recommendations.

National Center for Children in Poverty. (2010). *English language proficiency, family economic security, and child development.* New York, NY: National Center for Children in Poverty.

National Council of La Raza. (2004). *The health of Latino communities in the South: Challenges and opportunities* (Department of Health and Human Services – Office of Minority Health). Atlanta, GA: National Council of La Raza.

National Council of La Raza. (2005). *Health care funding overview*. Retrieved from http://www.nclr.org/index.php/publications/health_care_funding_overview/

National Council of La Raza. (2006). *Redefining HIV/AIDS for Latinos: A promising new paradigm for addressing HIV/AIDS in the Hispanic community* (Institute for Hispanic Health). Washington, DC: National Council of la Raza.

(2005). *National health disparities report.*

(2005). *National health policy forum*.

National Institute of Allergies and Infectious Diseases. (1997). *HIV infection in African American women.*

National Institute of Allergies and Infectious Diseases. (2004). *HIV infection in women.*

National Institute of Health. (1998). *HIV infection in women*.

National Minority AIDS Council. (1999). *Latino and AIDS video.*

Norman, E. (2000). *Resiliency enhancement: Putting the Strengths Perspective into social work practice.* New York, NY: Columbia University Press.

O'Connor, M. (1997). *Treating the psychological consequences of HIV.* San Francisco, CA: Jossey-Bass Publishers.

Office of Minority Health Resource Center (2003). *Minority HIV/AIDS Initiative*.

Okun, B. F. & Ricki, E. (2007). Effective helping: Interviewing and counseling techniques (7th ed.). In R. R. Greene (Ed.), *Social work practice: A risk and resilience perspective (1st ed.).*

O'Leary, A. & Jemmott, L. S. (1996). *Women and AIDS: Coping and care.* New York, NY: Plenum Press.

Ostrow, D. G. (1997). Disease course and psychiatric manifestations of HIV. In M. O'Conner (Ed.), *Treating the psychological consequences of HIV.* San Francisco, CA: Jossey-Bass Publishers.

Padgett, D.K. (1998). *Qualitative methods in social work research: Challenges and rewards.* Thousand Oaks, CA: Sage Publications.

Padilla, A. & Keefe, S. E. (1984). The search for help: Mental health resources for Mexican-Americans and Anglo Americans in a plural society. In S. Sue & T. Moore (Eds.), *The pluralistic society: A community mental health perspective.* New York, NY: Human Sciences Press.

Padilla, A. M. & Salgado de Snyder, N. (1985). Counseling Hispanics: Strategies for effective interventions. In P. Perderson (Ed.), *Handbook of cross-cultural counseling and therapy* (pp. 157-164). New York, NY: Praeger.

Pequegnat, W. & Szapocznik, J. (2000). *Working with families in the era of HIV/AIDS*.

United States: Sage Publications, Inc.

Perkins, K. & Tice, C. (1995). A strengths perspective in practice. Older people and mental health challenges. *Journal of Gerontological Social Work, 23*(3/4), 83-97.

Pfizer Inc. & Pfizer Foundation. (2006). *Pfizer Foundation HIV/AIDS Initiative.* Retrieved from http://www.pfizer.com/pfizer/subsites/philanthropy/programs.jsp

Phillips, M.H. & Cohen, C. S. (2000). Strength and resiliency themes in social work practice with groups. In E. Norman (Ed.), *Resiliency enhancement: Putting the Strengths Perspective into social work practice*. New York, NY: Columbia University Press.

(1998). Project Inform: Information, inspiration and advocacy for people living with HIV/AIDS. *Women and HIV/AIDS*, 1-12.

Radke-Yarrow, M. & Brown, E. (1993). Resilience and vulnerability in children of multiple-risk families. *Development & Psychopathology, 5*, 581-592.

Reif, S., Geonnotti, K. L., & Whettern, K. (2006). HIV infection and AIDS in the deep South. *American Journal of Public Health,* 96(6), 970-973.

Reimann, J. O. F., Talavera, G. A., Salmon, M., Nunez, J. A., & Valasquez, R. J. (2004). Cultural competence among physicians treating Mexican-American who have diabetes: a structural model. *Social Science and Medicine, 59,* 2195-2205.

Rios, E. (2006). *Latinas and the HIV/AIDS epidemic: Las olvidadas/the forgotten ones.* United States: The Hispanic Federation.

Rodríguez-Escobar, Y., Pomeroy, E., Holleran, L. K., & Noel, L. (2004). Culturally

relevant social work services for Latinas infected or affected with HIV/AIDS. *Social Perspectives*, 6(1/2), 63-81.

Rosenbluth, M. E. (1986). *A study of vulnerable and resilient young adults*. (Doctoral Dissertation), University of Chicago.

Rubin, A., & Babbie, E. (1997). *Research methods for social work (3rd ed.)*. United States: International Thomson Publishing Company.

Rutter, M. (1989). Psychosocial resilience and protective mechanisms. In Anthony & Cohler (Eds.), *The invulnerable child* (pp. 181-221).

Saleebey, D. (1996). The Strengths Perspective in social work practice: Extensions and cautions. *Social Work*, 41(3), 296-305.

Saleebey, D. (1997). *The Strengths Perspective in social work practice (2nd ed.).* White Plains, NY: Longman Press.

Sandoval-Cros, C. (2009). Hispanic cultural issues in end-of-life care. In K. J. Doka & A. S. Tucci (Eds.), *Living with grief: Diversity and end-of-life care*. Washington, DC: Quality Books.

Santiago-Rivera, A. L., Arredondo, P., & Gallardo-Cooper, M. (2002). *Counseling Latinos and la familia. A practical guide.* Thousand Oaks, CA: Sage.

Shapiro, M. F., Morton, S. C., McCaffrey, D. F., Senterfitt, J. W., Fleishman, J. A., Perlman, J. F., . . . Bozzette, S. A. (1999). Variations in the care of HIV-infected adults in the United States. *JAMA, 281*(24), 2305-2315.

Shedin, M. G. & Shulman, L. C. (2002). *HIV prevention community planning: An*

assessment of Latino populations in seven states. United States: United States-Mexico Border Association.

Shilts, R. (1987). *And the band played on.* New York, NY: Penguin Books.

Smart, J. F. & Smart, D. W. (1991). Acceptance of disability and the Mexican American culture. *Rehabilitation Counseling Bulletin, 34*(4), 357-368.

Southern Exposure. (2010). *Human rights and HIV in the southern states.* Retrieved from http://www.hrw.org

Southern States Manifesto. (2003). *HIV/AIDS and STDs in the south: A call to action.* Retrieved from http://www.hivdent.org/Manifesto.pdf

Spradley, J. P. (1979). *The ethnographic interview.* New York, NY: Holt, Rinehart & Winston.

Starfield, B. (1998). *Primary care: Balancing health needs, service, and technology.* New York, NY: Oxford University Press.

Sudbury, J. (1998). *'Other kinds of dreams': Black women's organizations and the politics of transformation.* London: Routledge.

Sue, D.W. (2006). *Multicultural social work practice.* Hoboken, NJ: John Wiley & Sons.

Taylor-Brown, S. (1998). Talking with parents about permanency planning. In D. M. Aronstein & B. J. Thompson (Eds.), *HIV and social work: A practitioner's guide* (pp. 349-359). Binghamton, NY: The Haworth Press, Inc.

Texas Department of Health. (2003). *Annual report.*

Texas State Data Center. (2005).

Texas State Historical Association. (n.d.). *The handbook of Texas online.* Retrieved from http://www.tshaonline.org/handbook

Texas State Historical Association. (n.d.). *South Texas plains.* Retrieved from http://www.tshaonline.org/handbook/online/articles/ryslr

Thebody.com. (2007). *Protease inhibitors.* Retrieved from http://www.thebody.com

Thrasher, S. P. & Mowbray, C. T. (1995). A strengths perspective: An ethnographic study of homeless women with children. *Health and Social Work, 20*(2), 93-101.

Trisdale, S. K. (2005). *The Well Project: Domestic violence and HIV*. Retrieved from http://www.thewellproject.org/en_US/Womens_Center/Domestic_Violence_and_HIV.jsp

U. S. Census. (2001).

U. S. Census. (2002).

U.S. Department of Housing and Urban Development. (2005).

U.S. Department of Labor. (2004).

U. S. Public Health Service's Office on Women's Health. (1998). Fact sheet. *The Health of Minority Women,* 1-17.

Visotsky, H. M. (1961). Coping behavior under extreme stress: Observations of patients with severe poliomyelitis. *Archives of General Psychiatry, 5*, 423-448.

Walsh, F. (1998). *Strengthening family resiliency.* New York, NY: Guilford Press.

Weaver, H.N. (2005). *Explorations in cultural competence: Journeys to the four \ directions.* Belmont, CA: Brooks/Cole.

Weick, A. (1983). A growth-task model of human development. *Social Casework, 64*(3), 131-137.

Weick, A. (1986). The philosophical context of a health model of social work. *Social Casework, 67*(9), 551-559.

Weick, A., Rapp, C. A., Sullivan, W. P., & Kisthart, W. (1989). A strengths perspective for social work practice. *Social Work, 34*, 350-354.

Werner, E. E. & Smith, R. S. (1992). *Overcoming the odds: High risk children from birth to adulthood*. Ithaca, NY: Cornell University Press.

White, R. (1991). *Ryan White: My own story*. New York, NY: Dial Books.

White, R. W. (1974). Strategies of adaptation. An attempt at systematic description. In G. V. Coelho, D. A. Hamburg, & J. E. Adams (Eds.), *Coping and adaptation* (pp.47-68). New York, NY: Basic Books.

Wikipedia. (2010). *Deep south.* Retrieved from http://en.wikipedia.org/wiki/Deep_South

Wilder, T. (2002). *Twenty years of women living with HIV: Past, present and future.* Retrieved from http://www.thebody.com/columnlists/wilder/20years/1986.html

Wolf, E. (2002). The HIV timeline: 1980-2001. *Journal of HIV/AIDS and Social Sciences*, 1(1), 11-23.

Wolin, S. J. & Wolin, S. (1993). *The resilient self: How survivors of troubled families rise above adversity.* New York, NY: Villard Books.

World Bank Organization. (2000). *AIDS and poverty: Who needs help?* Retrieved from http:///www.worldbank.org/aidsecon/arv/conf-aids-4/ch4-1pg3.htm

World Institute on Disability. (2002). *Disability world*. Retrieved from

http://www.disabilityworld.org/09-10_02/news/latinos.html

VITA

Yolanda Rodríguez-Escobar resides in her home town of San Antonio where she attended Sidney Lanier High School. She received both undergraduate and graduate degrees in Social Welfare from the University of California, at Berkeley in 1981 and 1983. Her research interests include women's issues, community health, HIV/AIDS, health disparities among people of color, specifically as they relate to the Mexican-American population. She has a special interest in cultural/gender-specific service delivery. She is currently teaching at the Worden School of Social Service at Our Lady of the Lake University where she holds the position of BSW Director. She has taught in the area of direct practice, human behavior in the social environment, social work practice and policy. She is interested in teaching in the subjects of grief and loss, culture diversity/competency, community organization, gender studies, and health disparities among people of color.

Permanent Address:

Yolanda Rodríguez-Escobar
2224 Fresno
San Antonio, TX 78201
TinyYoli@aol.com

This dissertation was typed by the author.